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ABSTRACT

This paper presents results from interviews with 48 New York families of children with severe disabilities or chronic illnesses who were served by Sick Kids (need) Involved People (SKIP) of New York, Incorporated, a case management and advocacy service. The report is divided into sections on the families and their children, daily routine, specialized care, impact on the family, informal supports, financing home care, services to the child, family supports, effectiveness of SKIP management, families' views of the future, crucial issues, and conclusions. In the concluding section an impression emerges of a schizophrenic system of public and private supports for home care for children with severe disabilities and specialized health care needs. The experience of families did not support the rhetoric of public offícals on the centrality of home, community, and family in service delivery. An appendix outlines methodological considerations in evaluating family support programs. Listed are 22 references. (PB)

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COME TOGETHER:

THE EXPERIENCE OF FAMILIES OF CHILDREN WITH SEVERE DISABILITIES OR CHRONIC ILLNESS

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COME TOGETHER:

THE EXPERIENCE OF FAMILIES OF CHILDREN WITH SEVERE DISABILITIES OR CHRONIC ILLNESS

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This report documents a fundamental social change which is being realized in the lives of the families you will meet in the following pages. Hence the grant (No. MCJ-365004) from the Maternal and Child Health Program which supported this report is appropriately entitled "Families and Communities in Transition" (FACT). Those of us involved in the preparation of this report see it as an effort to share the experience of these families with the hope that this information will make some small contribution to easing the the task confronting the next families who have similar challenges.

One person has to sit down and write the report of a project like this, yet this is only the last step in an extended interactive process to which numerous individual have made significant contributions. At SKIP of New York Margaret Mikol and Kathy Schwaninger have provided a constant, yet very gentle, goad for the completion of this report. Margaret Mikol, Carmen Soto, and Natalie Giuffi brought considerable skill, dedication, and compassion to the very difficult role of collecting the data reported here. Throughout this process the FACT advisory board has provided a compelling forum for working out many of the practical issues involved in this evaluation effort. The members of the board include Karen Buckholtz, Nina Daratsos, Aaron Favors, Gary Fitzgerald, Luann Kennedy, Kathryn Kirkhart, Barbara Kenefick, Suzanne Leach, Katie McKaig, Barbara Donaghy, Linda Reese, and Ed Walsh.

At Human Services Research Institute numerous staff members made significant contributions to this effort. Valerie Bradley's always dependable direction help steer this project through myriad competing demands to final completion. John Agosta wrote the first draft of the data collection instrument and provided an always fruitful sounding broad for discussion of subsequent revisions and resolution of problems in data analysis. Kathleen Moore coordinated data entry and managed processing of the quantitative data. Lasell Whipple immersed herself in the transcription of the interview data. Finally, Paul Nurczynski turned his sharp eye and nimble fingers to finalizing this report.

Over and above the contributions of all the individuals listed above, this report was dependant on the goodwill and cooperation of the families who agreed to share their daily experience with the rest of us. All of us involved with this project are immensely grateful to them for this opportunity. It is their contribution that is the heart of this report.

Introduction

This report is the story of 48 families. They represent the complete range of cultural, ethnic, religious, and economic diversity found in New York state. They live in run down public housing in New York City where they lock themselves in for their own protection and they live on acres of land in rural upstate New York. They range from anonymous single parent families who are barely subsisting on welfare to nationally known celebrities who had six figure incomes. And yet the story they tell here is surprisingly the same. In every case, the diversity of these families has been overshadowed by the fact that they all have been transformed by a child with a severe disability or a chronic illness.

It is true that each family and the situation of each child, all of whom have relatively low incidence conditions, is unique. And yet the clear message that comes through in extensive conversations with these families is that it is a major disservice to these families to write off their experiences as solely individual problems. These families as a group have something to teach anyone who has the good sense to listen to them. The commonalties which transcend their diversity clearly point to issues of social significance that merit the attention of decision makers in health and social policy at the local, state, and national level.

Methodology

The aim of this study is two fold. First, an effort was made to understand the experience of these families and communicate that experience to policy makers and service providers. Second it is intended to evaluate a case management and advocacy service provided to these families by Sick Kids (need) Involved People

(SKIP) of New York, Inc.. In order to achieve these dual objectives a 56 page data collection protocol was designed by Human Services Research Institute in consultation with the case management project advisory panel. The protocol attempted to integrate standard forced choice questionnaire items, which are amenable to statistical analysis, with open ended items, which allowed the families to talk about how they actually thought about the question or to describe their experience related to a particular aspect of home care.

This protocol was then administered to the families by case workers from SKIP who were familiar with each family. In this way the usual resistance of informants to be really open with a strange interviewer was over come. The interviews lasted anywhere from three to seven hours and yielded an incredible amount of rich descriptive information.

The unprocessed data forms were submitted to HSRI where all data analysis and preparation of this report were performed. All responses to questionnaire items were coded and descriptive statistics generated using SPSS (Statistical Program for the Social Sciences). All interview notes were transcribed into a standard form on a personal computer using Microsoft Word. These qualitative data were subsequently read at least three times. During these readings recurring topic and common experiences were identified in an effort to organize the common "themes" which capture the experiences of these families. It is these themes which form the basic organization of this report. As noted above the identification of these themes was relatively easy, since, the common experience of these families is remarkably similar. During the final reading of the field notes the individual examples from each interview which gave the best expression to the experience of the whole group were identified for inclusion in this report.

This approach does have the obvious limitation of involving the agency under evaluation in the process of the evaluation. However, the benefits derived from the already established relationship between the data collectors and the informants seems to far outweigh this limitation. As the discussion in Appendix 1, "Methodological considerations in evaluating family support programs," clearly demonstrates such an approach which depends heavily on the informants' reaction to their experience with a family support program is probably the most effective mode of evaluation. It is true that the informants are not likely to be truly critical of the SKIP program to a person who represents that program. Yet, the bulk of the information collected about each family's experience dealing with the systems of supports for themselves and their child confirms the substantial contribution which SKIP has provided to these families. As we shall see in a subsequent section of the report the value of the SKIP service is confirmed when the vast majority of the informants respond to the open-ended question "What group or individual has been the greatest help to you in you efforts to provide for your child's care at home" by identifying SKIP.

One Family's Journey

As an introduction to the themes which follow we would like to offer the experience of one family, as drawn from their interview and the observations of their SKIP contact person, as an archetype for the experience of all these families. As the result of specialized care needs of their daughter Irene*, this family has in many ways undergone the most radical transformation. And yet we chose them as our introductory exemplar because the profound change which they experienced highlights the common experience of all these families.

---

* This is a pseudonym, as are all the names used in this report.

> Irene came to the United States when it was discovered that the she required cardiac surgery. The surgery could not be done in her native country. Her grandfather is the head of the major University Hospital and consulted with colleagues across the United States. She was brought to this country by the Open Heart program.
>
> Upon initial examination Mom and Dad were told "not to worry" - this would be a quick fix-it job and she would return home quickly. The surgery to place a band around Irene's main artery was performed, and there were severe post operative complications.
>
> Mom kept telling the surgeon that the child looked worse than prior to the surgery. Her English was limited. The doctor "patted" her on the head and told her she was not used to these major surgeries and the child was fine. The child subsequently dropped blood pressure and had to be brought back to surgery. The band placed on her heart was too constricting. This happened two more times.
>
> In the interim her respiratory status was also compromised that she needed to be mechanically ventilated. Mom was getting worried about the expense of the operation and length of stay because she was told that she would be in this country for about 6 weeks - it was now 3 months, Irene's health was not improving because she was subjected to so many infections in the hospital, and her three other children were still at home in the Caribbean.
>
> Mom and Dad (who had come back to the U.S. for each surgery) decided to move the family to this country. They settled in a one bedroom apartment near the hospital just waiting for Irene to improve (which she did not). Mom had daily battles at the hospital because she was such a good and involved observer. She had a two day battle to get the child seen by an outside consultant because the child was being maintained on an adult ventilator and Mom thought that this was wrong. The consultant agreed and Irene, who was six months old at the time, was placed on a pediatric ventilator (she did much better).
>
> Battles of this nature were constant and protracted. The hospital insisted on weaning her each time a new resident came on because there was no physiological reason for the child to be ventilator supported 24 hours a day. The hospital also started telling the family to place Irene in a long term care institution, go home to their country and get on with their lives.
>
> Mom: "I almost went through the sky!"

The family also worried about the cost of hospitalization. Open Heart had experience only with short term funding and was paying $5,000 per month for Irene in the hospital. Mom then saw a news report about home care and SKIP and called for some assistance.

She was informed by SKIP staff that she was Medicaid eligible and that if SKIP could transfer the Open Heart dollars private insurance could be purchased for the child and family. (the parents had to also care for the other children who had to acclimate to new schools and new cultures.)

Mom said that Medicaid had turned the family down. SKIP explained that only the child would be eligible and the hospital had advised the family to apply for the entire family. There are several state statutes that allow for a child in these circumstances to be Medicaid eligible. The application process from the hospital took four months to correct. County Medicaid once again illegally turned down the application (the family wanted the child home) and their decision was turned down and reversed in a fair hearing. The State Commissioner of the Department of Social Services was brought in to expedite this decision. Negotiations were also being conducted with the Open Heart program to get the available resources ($60,000,00 for hospital care) transferred to $9,000.00 to buy a private insurance policy through a private group plan that was available to the family through the mother's professional organization

The hospital was hesitant and reluctant to allow for this process, because they were not too excited about demonstrating to their funders, Service Clubs and Open Heart, that "a case could go sour." The administrator told the parents that kids had died but never this MESS! Eighteen months of negotiations and documentation by SKIP and the family enabled the Medicaid and insurance arrangements to be made.

The battle then shifted to getting the staff to train the parents to take Irene home. Mom did all of Irene's primary care at the hospital but they would not start formal training until the payment for home care was set up. The family developed a very strong tie to a bilingual pediatrician who began helping them and appreciating how qualified the parents were to provide the care.

The hospital staff was resistant to train Mom in CPR and insisted that she call an ambulance in case of any emergency. SKIP had to get the department of health involved by citing the discharge planning regs because the hospital would not take advice from "novices," like us. SKIP's Medical Board members had established doctor to doctor contact, but even their suggestions were not heeded.

After months of draining struggles the child was reunited with her family. All told Irene had ended up spending two years in the hospital with her family there between 16-24 hours a day.

The home care setting has worked out very well. Irene has been weaned from the ventilator and only needs oxygen at night. She requires a lot of monitoring and even though she is exposed to typical school viruses by her sibs, has done well.

Her medical management has been switched to a different medical center and her local pediatrician (the one who was sympathetic in the hospital) follows her in cooperation with the family. They are hoping to decanulate* Irene this summer and her progress is astounding.

Once the insurance was worked out the durable medical equipment (DME) provider put an enormous amount of effort into supporting the family ("with things they did not need"). The child only needed oxygen as support occasionally and there was a four month supply of oxygen on hand stored in the garage at all times. The oxygen was bleeding off and being charged to the insurance. SKIP staff showed this to the family and ¼ of the tanks and supplies were removed.

The cost of the DME per month went down 60%. Trach cleaning kits at $50 per kit which were supplied but not medically necessary were also eliminated. Staff also helped the family to organize the child's room and environment so that a medical emergency could be managed in an effective manner. Mom and Dad said that when Irene got into trouble the first time with a plugged trach, if staff had not helped them prepare in advance for the emergency they would have lost her.

Both parents have training and education in fields which they cannot pursue in the U.S. They went from a very secure financial background to a life of near poverty by U.S. standards. Dad, who has a master's degree in safety and management of dairy products ("a much-needed skill in our country") is now working at Burger King as a manager. They are still having so many problems with their visa and green card that it required intervention from the White House. Mom cannot practice law in this country without passing the NY state Bar and she just does not have the energy. Their lives are suspended and they want to go home. They have a large extended loving family and they miss them terribly. The other children also want to go home. They visit periodically and really miss the closeness of their huge family.

They do not complain but they long to go home. But, they will not do this until Irene is medically stable.

Mom and Dad find the nursing intrusive and invasive. The nurses require a lot of training to manage the child and are not receptive to the family as a large entity. Dad "stays at work and Mom yells" (we all laugh).

This family loves their child and has been strengthened by all they've been through. They feel that her health status has improved greatly because of home care, and they feel that her medical management would have continued to be "a tug of war". Since "coming home" Irene is so

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* To remove breathing tubes inserted in nostrils to administer oxygen.

> different. She rules the world and has come out of her scared shell. The family feels like a unit and able to take on the battles because Irene is home.

Surely, the reader may ask, this tale of geographic dislocation and constant struggle with multiple bureaucracies cannot stand as an archetype for 47 other families. It must be pure hyperbole. As you shall see this family is a very appropriate exemplar. True, the other families do not experience literally geographic relocation, but they do find themselves transported by a series of uncontrollable events into a whole new world. Their lives are changed. They find themselves in alien environments where they are forced to deal with a foreign language in a struggle for the well being of their child and family. Most find themselves pushed to economic limits which they never thought imaginable. They find their social world redefined. In an effort to do the most natural of things--care for their own child--they find themselves confronting a multitude of public and private gatekeepers, anyone of whom seemingly has the ability to thwart their efforts. They find themselves involved in a constant round of begging, cajoling, and appealing to higher authorities often in an effort to obtain the most modest degree of assistance in getting their child's specialized needs met within the home. Yet, with all this, they do persevere and have succeeded in their efforts. Moreover, they are able to readily identify how all this struggle has had a positive impact on them.

In large part this report is the product of these families. They were willing to directly open their homes and their hearts to the interviewers. In so doing they indirectly let the rest of us into some of the most private areas of life. There is no question that this effort along with so much else that these families has endured has exacted a cost from them. And for that expenditure of self we should all be grateful. By pooling that most personal of resources, their own story, these families have convincingly provided a common story which demonstrates a pattern of policy and professional behavior which seriously threatens families who encounter it. **The testimony of these families calls on policy makers across the public and private spectrum to really examine whether the ever present rhetoric about the centrality of home and family life is supported by the day-to-day practices in their organizations**. Finally, the openness of these families imposes a requirement on the readers to really listen to them and hear what they are saying.

Organization of Report

There are twelve section in the balance of this report: 1. The Families and Their Children, 2. Daily Routine, 3. Specialized Care, 4. Impact on the Family, 5. Informal Supports, 6. Financing Home Care, 7. Services to the Child, 8. Family Supports, 9. Effectiveness of SKIP case management, 10. The Families' View of the Future , 11. Crucial Issues, and 12. Summary and Conclusions. The first eight sections reflect the major topic areas in the interview protocol, while the latter 4 provide an opportunity to discuss global issues in the lives of these families.

The first eight sections have a parallel structure. They begin with a presentation of the descriptive statistics from the questionnaire items related to each topic area. This is followed by a presentation of the relevant interview data. In the interview section a heavy emphasis is placed on allowing the parents to speak for themselves. Wherever possible the presentation in these sections relies on direct quotation from the field notes in the form of parents comments or observations by the data collector.

In regard to the use of quotations within this report, it is necessary to make two points. First, these quotes have only been slightly modified to assure anonymity to the families and clarify any problems of comprehension which result from the quotes being taken out of context within the interview process.* Second, in selecting a quote an effort has been made to assure that although the specifics of each situation are unique the central point stands as an exemplar for the experience of the entire group. In general, we have consciously avoided using quotation which describe a set of circumstances which is entirely idiosyncratic to one family or a very small group of families. In those cases where the quotation refers to very specific circumstance we point that out. For example, in the first section we use the parents, or interviewers, description of individual children to highlight the diversity of this group that can be lumped together as "severely disabled," "chronically ill," or "low incidence disorders." But, to reiterate, the bulk of the quotations are selected to be generalizable to the experience of the entire sample.

The last four sections of the report are drawn almost entirely from interview data and our synthesis of the information contained in this report. Here we continue to use direct quotation from field notes as a major part of our data presentation. In these sections we have observed the rules, outlined above, regarding the use of quotes which are generalizable.

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* In this regard, it should be noted that each quotation is followed by a two digit number in parenthesis. This is a randomly assigned identifier to assist in the management of data and to allow the reader to identify quotations which come from the same source.

The Families and Their Children

The 48 families included in this study are approximately 25% of all families served by the SKIP case management pilot project from June, 1987 to June, 1988. They were interviewed between May and September of 1988. Of this group nine lived in the Bronx, seven in Queens, two on Staten Island and four in Brooklyn, six on Long Island, six in Westchester and other northern suburban communities, and eight in upstate urban areas and rural areas.

In 43 of the 48 cases one of the birth parents of the child with specialized needs was interviewed for this report. The average household in the study group had 4 residents. In 21% of the cases there was a single parent, while the balance had two or more adults in the home. Respondents indicate that in 71% (n=34) of the cases the mother was the primary caregiver. The father fulfilled this role in 2 cases and grandparents in 1 case. The balance of the respondents (23% , N=11) indicates "other" or left this item blank. A review of the forms indicated that in many of these latter cases a nurse or other home health care worker was identified. The average household in the study group has an income in the $20,000-$29,999 per year range. Table 1 provides a break down of the income distribution of the sample group.

As Table 2 shows the children with specialized needs in the study group were relatively evenly distributed across the age range of 1 to 14 years of age. The average child was just over 6 years old. Seventy five percent of the families said the child's disability was identified at birth or shortly thereafter. A total of 92% were diagnosed by 5 years and all before the child was 10. The study group contained slightly more females (54%, n=26) than males (44%, n=22).

TABLE 1:
1987 TAXABLE HOUSEHOLD INCOME

Annual Income Range	*Percent of group*	*Number*
<$10,000	29.0%	14
$10,000-$19,999	16.7%	8
$20,000-$29,999	14.6%	7
$30,000-$39,999	14.6%	7
$40,000-$49,999	4.2%	2
>$50,000	21.0%	10

TABLE 2:
AGE OF CHILDREN WITH SPECIAL NEEDS IN STUDY GROUP

Age in Years	*Percent of group*	*Number*
under 1	4.2%	2
1	8.3%	4
2	14.6%	7
3	6.3%	3
4	12.5%	6
5	8.3%	4
6	6.3%	3
7	8.3%	4
8	4.2%	2
9	6.3%	3
10	6.3%	3
11	6.3%	3
12	2.1%	1
13	2.1%	1
17	2.1%	1
18	2.1%	1

TABLE 3: PERCENTAGE OF STUDY GROUP WITH VARIOUS DISABLING CONDITIONS

CONDITION	*PRIMARY DIAGNOSIS*	*SECONDARY DIAGNOSIS**
OTHER	29.17%	27.08%
CEREBRAL PALSY	12.50%	6.25%
BIRTH DEFECTS	12.50%	
MENTAL RETARDATION: PROFOUND	10.42%	14.58%
HEART DISEASE	6.25%	2.08%
TRAUMATIC BRAIN INJURY	6.25%	
MUSCULAR DYSTROPHY	6.25%	
BRONCHOPULMONARY DYSPLASIA	4.17%	12.50%
SPINA BIFIDA	4.17%	
ASTHMA	2.08%	6.25%
AUTISM	2.08%	2.08%
NEUROMUSCULAR DISEASE	2.08%	
CYSTIC FIBROSIS	2.08%	
VISUAL IMPAIRMENT		29.17%
EPILEPSY		16.67%
HEARING IMPAIRMENT		12.50%
ORTHOPEDIC IMPAIRMENT		8.33%
LEARNING DISABILITY		4.17%
EMOTIONAL DISTURBANCE		2.08%
TUBEROUS SCLEROSIS		2.08%
MENTAL RETARDATION: MODERATE		2.08%

• 37 INFORMANTS IDENTIFIED ONE OR MORE SECONDARY DIAGNOSES, 13 IDENTIFIED AT LEAST 2 CONDITIONS, AND 6 INDICATED 3 OR MORE

TABLE 4:
FUNCTIONAL CLASSIFICATION OF CONDITIONS FOUND IN STUDY GROUP

DOES YOUR CHILD HAVE A	PERCENTAGE INDICATING YES
CHRONIC MEDICAL CONDITION	97.90%
PHYSICAL DISABILITY	83.30%
SENSORY IMPAIRMENT	39.60%
BEHAVIORAL PROBLEM	27.10%

...WHICH SIGNIFICANTLY LIMITS HIS OR HER ABILITY TO PERFORM EVERYDAY ACTIVITIES AT THE LEVEL TYPICAL FOR HIS OR HER AGE?

Most of the children in the study group had complex medical histories which led in 81% of the cases to multiple diagnoses. The specialized nature of the children in this group is captured by the figures presented in Table 3. All of the diagnoses listed here, drawn originally from a Federal report on the incidence and prevalence of disability (Ashbaugh, Spence, Lubin, Houlihan, & Langer, 1985), have very small percentages associated with them. In a standard survey of children served by Special Education or Developmental Disabilities programs the distribution of primary diagnoses is quite different. For example, in this study group hearing impairment and visual impairment, major categories of disability in the national database, are always conditions which appeared secondary to a primary condition. The specialized nature of this group is underscored further by the fact that the largest single diagnostic category is "Other". This reflects the fact that the children in this group represent people who have some of the lowest incidence, rare disorders. These include such conditions as Oendine's Curse, Osteogensis Imperfecta, Rett's Syndrome, Dandy Walker Syndrome, CHARGE Syndrome, Nemoline Mypopathy, and others.

In the interviews many of the families recount how the rare nature of the child's condition led to two issues early on in the child's life. First of all it was often difficult to get a clear diagnosis. The parents tell of having to go looking for a physician who could tell them what was the matter with their child. Second, the rare nature of the condition has meant, in a number of cases, that the physicians have been unclear on the prognosis and have not known the most appropriate treatment.

Another way to conceptualize the characteristics of this group is to see how the children are described in terms of the type of condition they have. This information is provide in Table 4. A word of explanation is needed to clarify the significance of this table. All but one of these children (97.9%) was described as having a chronic medical condition. The remaining child was primarily described as having a physical disability. In addition, 81.1% of the group were described as having significant physical disabilities in addition to their medical condition. Similarly 39.6% of the children were identified as having a significant disability of sight or hearing (one child had limitations in both these areas). Finally, 27% said their child had a behavior problem. Half of that number sought outside help for the behavior. The most frequent problems were Self injurious behavior (12.6%, N=6) and stereotypic behaviors (10.5%, N=5). To summarize this group of children can primarily be distinguished from other children with physical disabilities, sensory impairments, behavioral problems, or other developmental disabilities by the fact that they **also** have very significant specialized health care needs.

These descriptive statistics create the illusion of a very homogeneous group. And indeed from a statistical perspective that may be true. However, it is equally important to understand the diversity found here. That only emerges as we listen to the descriptions provided by the parents and/or the interviewers. The seven examples that follow give some sense of the diverse nature of the children who are so central to this report.

> She is two and very age appropriate. She is starting to get interested in the potty. The exception is that Ryan has Oendine's Curse--sleep Apnea--and cardiac anomalies. She has a trach which needs to be watched and cared for. Must be on the ventilator while sleeping or else she will go into respiratory

arrest. Needs to be watched as any two-year-old. She is now standing on a stool at the kitchen sink playing with water. (03)

For nine months Michelle appeared healthy, then developed uncontrollable seizures. At three years she was diagnosed as being autistic with an uncontrolled seizure disorder. Dad said it would take at least 4 to 6 weeks of constant contact with her before someone could communicate with her. Simple commands are understood. She uses physical directions, pointing, etc. She has some receptive language skills. Diapers are needed. If she is told to pull up her pants she will sometimes do so, but will not dress on her own. She's in her own little world and is fascinated by letters on cans and road signs. She can sit for hours obsessed with letters.(11)

Sally is comatose due to smoke inhalation during a fire. She has breathing problems and brain damage. 80% of her brain is gone, but Mom notices some sort of memory. Glaucoma is setting in. She's on a ventilator 24 hours/day, has a gastrostomy, and needs complete physical attention. She has a heart monitor and needs to be bathed. She requires cardiac and respiratory monitoring. Vital signs must be checked every 24 hours. Must be rotated in bed to avoid bedsores. (15)

George is 17 years of age and has Muscular Dystrophy. Cannot move at will - requires total support--dressed in bed and must be lifted to commode chair. Mom says he has "too big a mouth" but never complains. Communicates well with others. Loves to play chess - family has adapted, by themselves - a stick with a toilet paper roll which he puts over the chess piece and then moves his chair to move the chess player to desired spot. He loves to watch TV late - and requires constant moving about every 1 hour - on a good night. He knows that his disorder is progressive and wants to be in control of the outcome. He sat in during most of the interview. His self image is so strong that he interjected that he felt these questions make him too much of a doctor's client! (23)

Pam is 2 years old and has what is called Dandy Walker syndrome (genetic disorder) because of this she is classified as profoundly retarded. She has bronchopulmonary dysplasia. She has hydrocephalus- but no shunt. Up till now has not had to have any fluid extracted. Physicians have told parents that Pam has very little brain mass--most of her brain consists of a tumor. She is a very active and alert child. Physicians are not sure how she is able to survive so alertly on such a small amount of brain tissue.(34)

Eva, age 7, is brain-damaged and in a semi-comatose state due to loss of oxygen during drowning incident. She is unable to move any part of her body. She will make faces and blink eyes in order to communicate. She is unable to speak. She responds to loud sounds. She becomes very frustrated, will cry when feeling uncomfortable.(44)

Stanley is 4 years old. Just before his third birthday he was struck by auto. As a result he has severe learning and motor disabilities. He will need assistance for the rest of his life. He doesn't require 24-hour hands-on care. He does need to be watched and needs a lot of physical intervention but has no trach or gastrostomy which would require more vigilance. He perseverates--gets on a topic and can't get off it. Becomes impulsive, stubborn. Refuses to do anything you ask. Has no sense of where things end. For example, if he were to be climbing stairs, when the steps end he would continue climbing in mid-air. Does not know where things end. Unaware of danger.(47)

Daily Routine

A somewhat more informative picture of the level of care which these families must provide for their children emerges when we ask them to simply describe the daily routine in the home. Here the emphasis is solely on the amount of support the child needs in the regular activities of daily life, not on any specialized care that may be required because of their condition. This functional measure of the child's level of disability or level of assistance as it relates to 10 activities of everyday life and a global measure of overall assistance need are summarized in Table 5.

As can be seen in Table 5 when we asked the caregiver to describe the degree of care/supervision the child needed during various periods of the day the consistent response for "complete supervision" was in the range of 70-80% of the respondents. The low figure on this group of items was "Free time," here the need for complete supervision dropped to 54% of the cases. When asked to rate the overall care needs of the child 81% described them as "extensive," the extreme rating on our scale.

A final measure of the day-to-day demands of care faced by these families can be found in the degree to which they find their sleep interrupted by the nighttime care of the child. A total of 41.7% of the informants said that the child did not sleep through the night on a regular basis . The majority of this group (55%) said this was not just a minor sleep disruption and was a cause for concern.

When we asked them to rate the care demands of the child against their expectation when the child returned from the hospital, 63% of the caregivers said the demands of care were much higher than they expected at the time they brought their child home. When asked to identify the period of the day which places the most demands on them 23% of caregivers identified the morning and 12.5% of them said "constant." 42% of the respondents said that no period of the day was more demanding than any other. However, when this last response is reviewed in light of the interviews the "no period more demanding" response seems to be indicative of a "constant" high level of care.

A "constant, high level of care" is a very dry measure on a Leikert scale. The reality in the lives of the families in the study group is something else. As the selected summaries presented here indicate, they are engaged in the hard work of personal care for most of their waking day.

> She will require diapers for the rest of her life. She is a fussy eater and won't eat for new people. She only eats foods that she likes so a proper nutritional balance is difficult. She is subject to fracture so Mom has to be careful, needing two hands, although the child loves bathing. Her bone structure does not allow self-grooming. She has specially made clothes with velcro so that none of her bones are damaged while she is being dressed. Starting to babble. Will say "Hi" to Grandma on the phone. She is wary of new faces and will not speak to them. She is not very mobile. She loves squeaky toys. She likes company and won't play alone. She has to be positioned in her infant seat. She cannot turn herself so she has to be repositioned. She wakes every two hours and gets n.g.* feeding at night. (02)

> Morris bounces out of bed quite early in the AM. He is aware that he needs to be quiet in early AM and will play for about 2 minutes before he bursts out of his room. Lisset gets up and monitors him at night to make sure things are checked out. He can aspirate, so meals must be organized. Two months ago he was yelling and he choked on rice. He went out and Lisset had to bag him and change his trach. When she did she found a rice plug. A new law of quiet and calm was set down for meal times. Because of the trach he has to be closely watched. He loves the water but must be watched. He loves bubbles but he can't blow them because of trach so he loves bubble baths. Needs help -- works at getting dressed by Lisset. He picks out his own clothing and Lisset can't shop unless he is along because

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* Nasal-gastric

he has his favorite colors. He caught his shirt on his trach once and is afraid to take it off alone. Putting socks on seems to be quite hard. Lisset feels that his arm muscles are a tiny bit underdeveloped and that movement compresses his chest. Voice -- "And what a voice" (Mom). He speaks quite well around his trach and has made leaps and bounds. His sense of humor is developing and he mimics his entire family. He calls his older brother "boy" and "waits for him to pop him." You have to watch that he doesn't get down because he will arrest if he doesn't get ventilated. Toys, TV -- he likes to go outside, loves playing LEGO. This little guy has a lot of energy and incredible stamina. He can play on his own and loves animals. His play is reality-based for a 4-year old, and he usually reenacts things that have happened. He can sleep through the night, but you have to make sure he does not disconnect himself. He has to be watched for restlessness because it means he isn't well ventilated. You also have to watch how he positions himself because he loves to sleep on his stomach. Once he is on the vent he will sing himself to sleep. Easy-going, OK kid -- doesn't like to go to bed. Likes to "hang" with the family (Aunt). He likes to listen to the sounds in the street in summer and Lisset can hear him talking up a storm before he winds down. He loves it when his cousin sleeps over. They stay awake laughing for hours. Morris was initially sent home to Cynthia,. his birth mother, who was 18 years old. They went home to live with Grandma. Cynthia burned out because she had no supports. She picked up and left one night just before her mother came home from work and moved to Kansas. (She has since moved back.) (04)

Mom bathes her twice a day, in the morning and evening. Mom weighs 107 lbs and daughter weighs 60 lbs, so she could use help lifting daughter into and out of tub.(12)

Jim needs constant help because he is subject to aspiration. He has to eat in a quiet environment because if he fools around he can aspirate and choke and go out quite easily. He loves to eat only drinks milk and water. He loves water, but his trach has to be kept clear - because of his level of activity you have to watch him at all times. He loves to mimic his brother and tried to dive--once. He also has a phrenic nerve pacer which you cannot get wet. His electrodes must be covered. Mom has to do teeth and hair - he can't do this alone. People have problems understanding Jim when they first meet him. He loves to meet people and is very social. He never sleeps through the night - he disconnects - he needs suctioning - tubing has to be monitored - need to listen to lungs on the ½ hour because he can change so quickly. Is checked 8 x per night! No one period of the day is the "most" stressful because his care is constant.(20)

TABLE 5:
LEVEL OF ASSISTANCE NEEDED BY STUDY GROUP MEMBERS IN VARIOUS ACTIVITIES OF DAILY LIVING

	PERCENTAGE OF STUDY GROUP REQUIRING...*		
Activity Area	***No Assistance***	***Moderate Assistance***	***Extensive Assistance***
TOILETING	14.60%	8.30%	77.10%
EATING & DRINKING	12.50%	16.70%	70.80%
BATHING	4.20%	14.60%	79.20%
GROOMING	4.20%	14.60%	77.10%
DRESSING	8.30%	18.80%	66.70%
COMMUNICATING	18.80%	14.60%	56.30%
PLAY	12.50%	27.10%	54.20%
MOVEMENT IN HOME	12.50%	14.60%	60.40%
MOVEMENT IN COMMUNITY	6.30%	8.30%	72.90%
CHANGING POSITION	20.80%	14.60%	54.20%
OVERALL	4.20%	14.60%	81.30%

* ALL ROWS DO NOT TOTAL TO 100% BECAUSE OF MISSING RESPONSES

Specialized Care

There were an extensive number of questions dealing with the exact nature of the child's care. These questions fall into three categories 1) medication administration, 2) medical monitoring procedure, and 3) specialized treatment or procedures which are performed on a regular basis. These specialized activities which are in addition to the regular supports provided to the children, as described in the previous section, are summarized in Tables 6, 7, and 8. The best summary of this very complex series of items is to say that merely totalling the numbers of procedures, treatments, and therapies most of these families perform affirms the "extensive" care needs of 75% of these children. This is further underscored by the fact 67% of the families perform some specialized clinical monitoring of their child on at least a daily basis. Fully 44% of the families summarize their care of their child by saying he or she needs 24 hour a day monitoring.

The experience of Gini and her mom is very typical of the other families in this study:

> She is essentially immobile, requires stimulation and a lot of intervention. Her respiratory status is compromised because of her chest deformities. 8 hours of LPN daily--monitors respiratory status and feeds--monitors her for fractures and bone problems. Gini gets n.g. feedings at night when she hasn't taken enough during the day. She is also on antibiotics to prevent infection. Positioning her is very tricky because she needs to be positioned so her bones are supported and won't fracture. She needs Delee traps, heart monitor, feeding tube, stethoscope, special seat and an adapted stroller. When she first came home her cardiac monitor was not set right and went off constantly. Now everyone can operate it better and things are fine. She is immobile, and must be moved. She can move her hands to her face but can't roll from side to side. She has to be carried, along with her heart monitor, special seat, Delee traps. If she is not strapped she will slide down, so positioning is critical. Mom takes her everywhere she goes.(02)

Another factor which complicates the lives of these families is the loss of privacy they experience as a constant parade of outsiders tramp through their homes.

> RN comes in three times/week to check vital signs. Oxygen is given twice a day. There is also portable oxygen; suctioning machines: portable and plug in. Meds three times/day. Pat is a baby; she doesn't know how much supervision he will need as he grows. Mom carries along portable oxygen machine when she and Pat go out. He doesn't need it all the time, but it is there if he does.(14)

> They used to have 24-hour nursing, but family got tired of lack of privacy, and they are taking more primary care giving responsibilities.(18)

As Margie's mom demonstrates "taking more primary care responsibilities" entails a lot.

> Margie is being weaned but needs constant monitoring: has to be constantly monitored for infection, and immediately treated. Margie can turn sour in a second and can require full intervention and requires medication - 12-24 hours of R.N. per day. She can still plug off and require intervention. For example, she is subject to bronco-spasm - and has underlying allergic reactions. Her medications include Lasix - Digoxin, Alupent Inhalant, and Cromalyn 4 times per day. All meds are P.O. to gastrostomy except inhalants - and she does not react to them except slightly elevates heart rate. Margie's care is rather straight-forward except the need for monitoring is much more detailed and involved if she is sick. She then requires constant care and her regimen becomes quite stringent in terms of monitoring and intervention. Her specialized medical equipment includes Oxygen, trachs, mist at night, suction equipment, portable oxygen, suction, compressor, heart monitor, oxygen monitor, ambubag, accumulator, suction catheters, portable nebulizer, trach strings, stethoscope, saline, sterile water, 60cc syringe, other size syringes for epinephrine, and trach filters. Mom is so used to it doesn't phase her. But the deliveries are not well coordinated and Mom has to scream a lot.(17)

One other measure of the extensive care needs of the children in this study group can be found in a mere inventory of the specialized equipment in each home. The vast majority of families (87.5%) reported such equipment. While in a few cases this entails only an item or two, most of these families supplied extensive lists of equipment. For families with children on oxygen this "specialized equipment" included such things as running tubing throughout their home so the child would not be restricted within the house. Of those families with equipment, 32% reported problems with monitoring it and 42% reported problems in getting service.

One family's inventory of equipment gives some sense of what all of these families deal with:

Suction machine: one battery operated, one stationary.
Compressors(2).
Oxygen tank and backup.
Big battery and 2 battery packs.
2 ventilators.
Syringes.
Tubing and saline.
Sterile water.
Delee: traps & filters.
Humidifier: saline ampules.
Peep valve, saturation machine wires and tapes.
Vapor phase.
Cardiac monitor.
Gloves. (03)

Another family's list of medication gives some meaning to the figures contained in Table 6:

Phenobarbital - 30 mg one every AM. 2 tabs every PM.
Ditropan - 5 mg. twice a day (enhances muscle control in bladder)
Vitamin C - 500 mg. - one tablet twice a day
Carafate - 1 gm twice a day (ulcers)
Prednisone (for swelling in head) - 2.5 mg once a day
Multi-vitamin - once a day
Collace - 100 mg. twice a day
Urinary tract prophylactic -- Septra DS - 1 tab every night for 10 days --
Ultraceph - 500 mg - 1 tab at night for 10 days, then go back to Septra
Senecot -- laxative -- PRN for constipation
Tylenol -- 325 mg - 2 tabs PRN for headache
Tylenol #3 for Severe headaches -- 1 tab every 4 hours (codeine)
Motrin for arthritic pain -- 40 mg. PRN
Mylanta/Antigel - when she has blood in stool -- PRN 30 cc every 2 hours.(48)

A further measure of the specialized care needs of these children and a sense of the subtle tension these families live with can be seen in the fact that 31% of the families reported that within the last month their child had experienced some sort of crisis which required an extraordinary intervention. Here once again, this number is relatively meaningless without the information contained in the interview. When we read the interviews we see that these families regard some of the events which most people would regard as a crisis as part of the routine of every day life. For example, some of these children need to be assisted with their breathing several times each day. So when these families describe an extraordinary event it usual entails a major accident, illness, equipment break down, or other truly life threatening event. In other words, events which most people would regard as life threatening but which these parents have learned to handle have now become routine to them.

For example, the following event which took place during the interview is **not** considered by the parent to be extraordinary. This is just one of the little day-to-day crises of life:

> Sukari was choking on a thick piece of mucous that couldn't be suctioned. The nurse wasn't able to clear her properly- mom jumped in and turned the child carefully. Gave several pats in the right spots and grabbed the suctioning tube, put it in trach and got the piece out within seconds. Child began breathing normally again and stopped coughing immediately. Mrs. Vasquez was calm through the entire process. It did not phase her at all. I commended her on her ability to stay extremely calm during that episode.(32)

On the other hand, failures of the support system often do precipitate crises which the families see as more serious. As in the case of Sally and a poorly handled change of equipment.

> The respiratory therapists were trying to get Sally on home ventilator. They tried switching from one system to another and it took two weeks to straighten it out, as Sally wasn't responding well to the switch. It took a week for dermatologist to check her for bedsores and hair fallout.(15)

Even simple things like a change in the weather can become a threat to the family:

> Mom and dad had an emergency with Pam. Dad called mom over while mom was getting together and let her know Pam was seizing. They were in the apartment, it was 11 pm. She seized for 3 minutes, lost her color, turned blue and lost consciousness. Mom administered oxygen, she became semi-conscious. She started to get color back, had called doctor, who had someone already waiting for her at emergency room. She was checked out by doctor who said that when ever the weather gets too much and the temperature goes up, she should expect her to seize.(34)

The situation which Jim's family must live with gives the reader some sense of the tension which can become just a regular part of life for these families.

> He can change so rapidly, can go from being fine to arresting in no time flat. You have to know his baseline status extremely well to even clinically evaluate him. You cannot take your eyes off his clinical status. Equipment has to be monitored constantly. Jim can need extraordinary intervention very quickly without warning. The person monitoring has to make sure they can troubleshoot the pacer as well as the ventilator and all of the other equipment that Jim needs. (20)

In summary, the example of Pete and his mother capture some of the reality behind the words "constant" care and "crisis" situation.

> Pete requires constant skilled care and continuous 24 hour monitoring (according to individualized criteria including behavior, coordination, cognitive function, level of activity, physical findings). His clinical condition is highly unstable and influenced by weather, fatigue, activity, etc. He has sudden episodes of severe wheezing and active distress and has required emergency resuscitative care on several occasions during the past year. We have confronted (1) Choking episode on solid food, loss of consciousness - Heimlick maneuver. Successful within 1 minute - at bedside all night watching for sudden onset of respiratory distress on MD's advice (severe episode complete obstruction). (2) Midnight asthma attack - severe - minimal BS cyanosis - responded to 40% oxygen, alupent mist IV aminophylline drip - all nighter. (3) a milder asthmatic attack requiring

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additional meds or allupent mist - total time 4 hours. (4) viral gastroenteritis, fever 102° danger of aspiration from vomiting while asleep--more all nighters. (30)

TABLE 6:
TYPE OF MEDICATION ADMINISTRATION REQUIRED BY MEMBERS OF STUDY GROUP

	PERCENTAGE OF STUDY GROUP REQUIRING				
Mode Of Administration	*At Least Weekly*	*1 Or 2x Daily*	*At Least 3 X Daily*	*As Needed*	*Row Total*
TOPICALLY	6.25%	4.17%	6.25%	6.25%	22.92%
ORALLY	4.17%	25.00%	12.50%	4.17%	45.83%
RECTALLY	4.17%				4.17%
INJECTION				2.08%	2.08%
INTRAVENOUSLY				4.17%	4.17%
VIA G TUBE		12.50%	14.58%	2.08%	29.17%
OTHER MODES		6.25%	8.33%	6.25%	20.83%

TABLE 7:
MEDICAL MONITORING PROCEDURES REQUIRED BY MEMBERS OF STUDY GROUP

	PERCENTAGE OF STUDY GROUP REQUIRING				
Monitoring Procedure	***At Least Weekly***	***1 Or 2x Daily***	***At Least 3 X Daily***	***As Needed***	***Row Total***
TEMPERATURE	27.08%	18.75%	29.17%	2.08%	77.08%
PULSE	25.00%	20.83%	29.17%		75.00%
RESPIRATION	16.67%	10.42%	31.25%		58.33%
BLOOD SAMPLE	52.08%	2.08%	2.08%		56.25%
WEIGHT	47.92%	8.33%			56.25%
URINE SAMPLE	41.67%	2.08%	4.17%	2.08%	50.00%
BLOOD PRESSURE	12.50%	18.75%	10.42%		41.67%
OTHER	14.58%	4.17%	16.67%		35.42%
LIQUID INTAKE/OUTPUT	6.25%	6.25%	18.75%		31.25%
STOOL SAMPLE	6.25%	4.17%			10.42%

TABLE 8:
SPECIALIZED TREATMENT OR PROCEDURES REQUIRED BY MEMBERS OF STUDY GROUP

	PERCENTAGE OF STUDY GROUP REQUIRING						
Treatment Or Procedure	*Weekly*	*Daily*	*Twice Daily*	*Every 4 Hours*	*Every 2 Hours*	*Constant*	*Row Total*
SKIN CARE		35.42%	8.33%	2.08%	4.17%	16.67%	66.67%
OTHER PHYSICAL THERAPY	41.67%	4.17%	4.17%	6.25%	2.08%	6.25%	64.58%
OTHER PROCEDURES	39.58%	4.17%	2.08%	2.08%		12.50%	60.42%
MONITOR VITAL SIGNS	14.58%	12.50%	4.17%	14.58%	2.08%	10.42%	58.33%
POSITIONING	4.17%	2.08%		8.33%	6.25%	35.42%	56.25%
TRACHEOSTOMY CARE	4.17%	2.08%	6.25%	12.50%	10.42%	16.67%	52.08%
FOOT CARE	27.08%		6.25%	4.17%		4.17%	41.67%
OXYGEN ADMINISTRATION	8.33%	2.08%	2.08%	2.08%		18.75%	33.33%
DENTAL CARE	16.67%	2.08%	8.33%	2.08%		2.08%	31.25%
GASTROSTOMY		2.08%	2.08%	14.58%	4.17%	8.33%	31.25%
INHALATION THERAPY	8.33%			12.50%	4.17%	6.25%	31.25%
STERILE DRESSINGS	2.08%	10.42%	10.42%	2.08%	4.17%	2.08%	31.25%
RANGE OF MOTION	2.08%	8.33%		4.17%	2.08%	12.50%	29.17%
BLOOD LEVELS	22.92%			2.08%		2.08%	27.08%
POSTURAL DRAINAGE			2.08%	14.58%	8.33%		25.00%
ORAL/NASAL SUCTIONING	2.08%	4.17%	2.08%	4.17%	4.17%	6.25%	22.92%
EYE CARE	16.67%			4.17%			20.83%
BLOOD SUGAR TEST	12.50%					2.08%	14.58%
NASAL GASTRIC FEEDING		4.17%		8.33%		2.08%	14.58%
EAR IRRIGATION	8.33%			2.08%			10.42%
ENEMAS	2.08%		4.17%			4.17%	10.42%
PARENTERAL FEEDING		2.08%			4.17%		6.25%

Impact on the Family

One series of items attempted to gain some sense of how the demands of home care effected the family's daily life. In this area it is really impossible to separate the answers to the survey items from the interviews. Each family has a unique story and the survey items only provided a forum to start them off in describing their experiences in caring for their child. It is in this area the interview data is the richest.

Perhaps the greatest impact of the child's disability is when the family must be physically separated because of the child's care needs. In the study group 17% of the children have been placed out of the home at some time. A measure of the pressure on the families can also be see in the fact that 27% of them have at least considered out of home placement for their child. It is also important to note this "out-of-home" placement means placement in an institution, nursing home, or community group home and does not include the extensive amount of time these children have spent in acute care hospitals or temporary respite.

In the area of employment, 31% of the prime care givers work out of the home at least part time. During the last year all of these individuals have had to take some time off from work because of the care needs of the child. Eighty percent of them had to take time off at least once a month. Additionally, 44% of the respondents indicated that a spouse or other adults in the home had to take time off from work. A third of these needed to take time off at least once a month.

Table 9 summarizes a group of, what might be called, the opportunity costs associated with home care. These are the major changes in life style, physical environment, daily routine, or opportunities for personal development which have been influenced by the care needs of the child with special needs

An example of this type of opportunity cost is seen in the 73% of the respondents who said their child's disability had effected where the family lived. When we look at the interview follow up to this question we find this takes three forms: 1) some families consciously chose to live in an area where they thought there were good services--the New York Metropolitan area, 2) some families chose to live in a neighborhood close to a hospital or clinic which would treat their child, and 3) many families found the expenses associated with the care of their child either made it impossible for them to move into the kind of housing they wanted or forced them to sell a home and live in an apartment or less expensive house.

In reviewing the families' comments that accompany their responses to the list of opportunity costs, it soon becomes evident that the list of categories, although useful to the researcher, does not capture the global impact which the child's needs often have on the family. As in the case of Jim's family, merely saying the child's disability influenced where the family lives hardly captures the reality behind that statement.

> Mom quit work; has to be home at all times. They live in a home with four generations of the family to cut down costs and to care for aging parents and grandmother. They cannot afford to live elsewhere because of Jim's expenses. Even with this proximity Mom cannot spend enough time with her dying mother because of Jim's care needs. The family's at the mercy of 15 different systems. They cannot fix or sell house because of the financial stress.(08)

In addition, to some of the obvious costs of care which have modified their lifestyle, a number of families speak of more subtle factors at work within their homes. Margie's family's cultural difference made them acutely aware of the need to be looking over their shoulders at the various professionals, with a different value system, who were always "evaluating" them.

> Knowing that Margie still needs a lot of nursing but it is so invasive. We do not seem to spend enough time as a family. It is bad always having therapists and nurses around. They do not understand what a "big Spanish" family looks like. We yell, we shout, we laugh, we hug--we are just a typical family. We need better and more discreet nurses. Some of our nurses work on other home cases and they speak about them so they must be speaking about us.(17)

The global transformation, which the families experience, usually begins at birth or shortly thereafter when the child's condition becomes evident. Many families tell very similar stories of being overwhelmed by the whole experience. This is often intensified by the hospital context and the demeanor of the professionals at birth. Many families tell of professionals dealing with them in a cold detached manner which only contributes to the confusion they are already feeling. Some recount a sense, or even accusations that they are to blame for their childs condition. In addition the attitude of the immediate and extended family is often formed by this initial negative experience. In many cases the family changes its attitude towards the child--but not always. The experience of Gini and her mother is illustrative.

> Mom had a long and difficult labor. The baby's deformities were visible at birth and the Ob-gyn. and pediatrician looked at Mom and said that it was her fault because she had smoked when she was pregnant. The condition is not related to that at all--it is a genetic defect that is inherited or a freak of nature. Mom was not shown the child for two days and was just told that the baby was in the neonatal unit. After two days the nurses came in and told her that babies get very well taken care of at institutions otherwise it gets too hard on the parents. She then brought Gini in. Mom cannot even describe her emotions or confusion. Mom thought about putting her up for adoption. The hospital suggested this and Gini's father said that Mom had

> to choose between him and Gini. Mom found out about the services she could get if she brought her home. Grandma went to visit a long term care home. Her reaction to this place impacted greatly on Mom's decision. The mom broke up with Gini's father more quickly since he will not get involved with the care of the child. (02)

Just as Gini's grandmother's exposure to institutionalization influenced that family's decision to provide home care, many other families recount a similar reaction which strengthened or actually formed their resolve to take their child home.

> While in hospital their son was on vent for 24 hours. Parents did not want to take child home on vent--especially 24 hours a day. Social worker and a nurse suggested Miller Memorial Hospital (a local long term care facility), to institutionalize the child. the parents were overwhelmed due to the one year of hospitalization, trach, tube feeding and ventilator dependency. They were thinking of placing him in Miller Memorial until he could breathe on his own. On SKIP's advice they visited Miller Memorial before making a decision. Immediately after visit they called and stated that they would not under any circumstances place their son in such an environment. They were shocked at the lack of stimulation and care children received there and felt their son would not receive the stimulation and caring that he needed. Instead, they chose to take him home even if he had to be on a vent 24 hours a day. Very shortly after the hospital weaned him off the vent, so he only required it during the night while sleeping, the family could not understand why the staff at the hospital had recommended such a place as Miller Memorial for their son After all, even though he is ventilator-dependent, he is an active, alert child who needs a healthy, caring, and stimulating environment.(07)

Once the initial shock is dealt with and the decision is made to care for the child at home most of the family speak of being totally unprepared for the radical changes that follow. One family responded to the inquiries in this area with a stream of consciousness inventory of physical, social, and psychological changes that are associated with the care of their child.

> Ran tubes in walls for oxygen and bought a van - small eating trays - purchase stands - and closet space for supplies. We have borne all expenses and done most of it ourselves. Paper towel - peroxide - food - phone bills - travel expenses to Chicago - electricity - extra phones - intercoms. Total lifestyle change - no flexibility as far as coming and going - Oxygen has to be

> measured - nursing services are restricted to in home care and no privacy - we do not entertain as much.

Another parents narrative of the effect which Jim has had on the life of his family also covers most of the bases. Particularly noteworthy in this excerpt is the emphasis on how Jim's needs have had an effect on his brother. This was a special area of concern in every case where the child with special care needs had siblings.

> I (Dad) can write a book on it (the changes in their life) - You lose all flexibility. The brother didn't have a normal 3rd and 4th year of childhood. He spent it in the hospital with his brother and he is very sensitive. The parents try to compensate. The family gets separated because they can't just get in the van and go. No spontaneity. Brother is too young but is starting to know the names of certain equipment and can help in a pinch. He often wants to just stay home with his brother. Mom can't seek outside employment because of Jim. Mom had to drop out of school. We are moving back to the city to be closer to the hospital - moving closer to friends, family and support. We cannot think about having another child. Jim is at home. Jim is striving towards being a typical kid - his brother loves him and is so glad he is home. Jim is happy and so adjusted. Mom feels all this made her a stronger person. It made our marriage stronger. Jim is a joy. Made the priorities clear - life is better defined.(20)

The extensive list of the child's disabilities, complex care needs, daily crises, effects on the family lifestyle, and other factors related to providing home care which we have reviewed thus far are powerful data. No family exposed to these forces can avoid profound stress and major changes. Yet the effect of these lists and percentages are somewhat deceptive. What is missing here is some measure of the positive results of the decision to care for the child at home. It is this positive impact that comes through only when we listen to the parents' stories.

The majority of families speak of the enormous improvement they witness in their child's physical and psychological condition, once they come home, as the most tangible affirmation of their decision to provide care at home. This is accompanied by an emerging awareness of their own capacity and competence as parents. When we probed concerning some less concrete outcomes of home care we heard the families talk about getting to know their child as a person, seeing them as a contributing member of the family, experiencing a sense of togetherness, a growing sense of personal strength, the reordering of the priorities in life, sibling learning about being caring people, and other factors which are not given to the same easy quantification as counting the pieces of special equipment that suddenly overflow into the family living room.

One family characterized the positive effect of their decision to care for their daughter at home in terms of finally being able to accept her as their daughter.

> The family (Mom and Dad) felt enormous stress. And as they look back on their feelings they considered Sissy an extension of her equipment. During last winter their nursing (24 hours per day) was cut back and the parents were obligated to provide the care. Mom feels like she thought she would have a nervous breakdown at first. Even though she was exhausted and nervous she realized she could meet the care demands -- she started bonding with Sissy for the first time since her birth. She said that smoother transition to fewer hours of nursing would have been better, but she made it through the situation and she feels good. Now even though the financing problems have been resolved she schedules less nursing to spend more one on one time with Sissy. Mom feels that this is a very bad way to learn a good lesson.
>
> They have gotten through the tremendous fear of her imminent death because she is doing better and as a result have allowed themselves to see her as other than an extension of her equipment.(18)

As the following excerpts from the interview with Pete's adoptive mother and Morris's uncle testify this need to see the child as a child--a unique growing human being--may be the positive out come of all these parent's experience. It is also clear from these and many other interviews, that it is this awareness which gives the families the strength to endure all they must confront.

> Most stress and dissatisfaction comes from outside sources. Pete has been a joy (despite his problems) and I have never regretted my decision to adopt him. I have learned (and I am still learning) from him everyday, both as a professional and as a mother. Pete's excitement about life and learning despite his severe problems, despite his past, is remarkable. His achievements, emotionally, academically, artistically over the past 3 years are amazing, considering his hospitalization in the ICU for 4 ½ years. Best of all Pete is a funny, bright, loving child who gets into lots of mischief to keep me busy, but who constantly makes me laugh (often at ourselves). Pete has enriched our family in a way that no one else could, and each of us has learned something about ourselves through him. Not one of us would trade a single hour with Pete for a winning lottery ticket. We're all very proud of him. Pete is the most loved member of his immediate and his extended family.(38)

> His Uncle, just came in on the interview and says: "Morris is a spoiled great kid who we all have ruined." (We all laugh). "The little king, we call him. The only one he minds is Mom. He looks at the rest of us like we are nuts. He loves to tag along with me but I worry that he will fall asleep if I take him too far. It is funny how this little kid wraps people and gets them to do the things he wants them to do. Mom never lets any of us carry on like that -- we would have had very sore backsides. She is funny too because she says she is hard on him, she is getting old and soft."
>
> Mom: "ALL RIGHT NOW!"(04)

Many of the parents, particularly the mothers, speak of the whole experience of fighting for their child as totally reordering their value system and giving them a very different perspective on their own competence. Charlene's and John's mothers make some of the strongest statements of this new growth in both self-awareness and social awareness.

> Mom has saved her life. Mom also feels that Charlene has saved her life and put things in order. Charlene has made Mom realize just what life means. Charlene has taught Mom about the practical application of health care. Patience - mom has learned - how to be frugal - keep a budget - self-reliance- independence - survival.(21)

> John has taught his mother the beauty of the power of each human life. John has made Mom a more socially conscious person and given Mom the best sense of worth in her entire life. Has spurred Mom on to help others. John introduced Mom to God. He has helped Mom to understand unconditional love, he has sharpened Mom's compassion for all disabled people and advocacy efforts, (all people) none of us is without a disability. He enunciates the shape we are in as a society. (25)

So, in summary, the families are very clear on the extensive costs that are associated with their decision to care for their own children at home. But, they are as a group very clear on the dividends they are accruing.

> Her sister is limited in her activities because when Ryan gets sick they don't want her exposed to new infections. Ryan has chicken pox today and is doing quite well. Cynthia (her sister) still drinks from a bottle when she is more upset. When Ryan is sick she'll want to stay home. She is rough with Ryan when she is well. Cynthia once pointed out to Mom that she was the only one getting punished so Mom took note of this and now there's more equalized treatment. In addition, Dad is working two jobs to make ends meet. Now he will be stopping this fall. He had to do this for insurance purposes. Nevertheless, we have a beautiful, happy, well-adjusted child and an intact family. The interviewer notes at this point: Ryan is now at the sink spraying water over all of us which captures what she is all about.(03)

TABLE 9:
IMPACT OF DISABILITY ON HOUSEHOLD

PERCENT OF HOUSEHOLDS REPORT...

83.33%	MAJOR CHANGE IN FAMILY LIFESTYLE
75.00%	MAJOR INCREASE IN HOUSEHOLD EXPENSES
72.92%	DECISION ON WHERE TO LIVE INFLUENCED
56.25%	SIGNIFICANT IMPACT ON SIBLINGS
54.17%	SOMEONE GAVE UP A JOB
41.67%	NEED TO MAKE PHYSICAL ADAPTATIONS
31.25%	SOMEONE DID NOT PURSUE EMPLOYMENT
29.17%	SOMEONE REFUSED A TRANSFER OR PROMOTION
29.17%	SOMEONE DID NOT PURSUE FURTHER EDUCATION
14.58%	JOB CHANGE FOR BETTER MEDICAL COVERAGE
14.58%	JOB CHANGE FOR BETTER HOURS

...BECAUSE OF CHILD'S SPECIALIZED NEEDS

Informal Supports

In the family support literature there is an increasing emphasis on the need for support services to be community based and built on the already existing resources of the family and the community. With this in mind, we felt it important to get some measure of how this informal system supported the families in the study group. A few of the survey questions which targeted this topic found that most of the respondents seem to have a relatively shallow informal system of support. Specifically, 54% said they get no assistance from a relative outside the household, 42% said they get no help from any non-professional outside the household, 21% said they had no one to turn to for aid even in a time of crisis, and 56% of those who were able to identify someone who they could contact for aid in a crisis, identified professionals who were already involved in the care of their child.

Unfortunately, in many cases the primary care giver tells of instances in which other family members are not able to accept the child with specialized needs or are resistant to the idea of home care. In several cases where this situation has led to divorce the informants indicate they feel the relationship was headed in that direction and the added pressures associated with the child's needs only hastened the inevitable. In most case the response to our inquiries in this area were very short without much elaboration.

> Husband and father pulled away, the rest of the family was shocked. They were relatively supportive. Mom got tired of explaining everything and avoided subject but stayed in contact without details. Mom's cousin will help with direct care.(36)

While essentially every family tells at least one tale of callousness, neglect, obfuscation, or arrogance on the part of professionals, many tell of long term relationships which go far beyond the limits of job description. It is little wonder families identify these professionals as some of the people they can depend on as "informal" supports

> Physician is excellent -- is there beyond the call of duty. I had an emergency on the doctor's wedding day. She was all dressed and ready to go down the aisle. She got on the phone and made sure that everything was taken care of for Ishtara.(40)

When it comes to the rather intangible quality of the psychological sense of community, the members of the study group did not feel particularly well connected to their communities and neighborhoods: 35.4% felt very isolated from their neighborhood. Another 22.9% felt somewhat isolated. In general, the interviews indicated this sense of isolation can at least be partially charged to their intense involvement in the daily care of their child. However, a number of families cited specific instances in which they felt the active resistance of their neighbors to accepting their child.

> A woman on the street chastised her for keeping her son in a carriage which reminded her that people have to be educated as to the needs of the handicapped. She doesn't believe that such children should be institutionalized, and that no one has a right to say that a child born with a disability should be automatically put away; that children have the right to be with their families.(13)

> They once took Margie to the public pool and the community "went crazy" so they are "nervous" to try that again - "we can be happy at home, so why try that again." (17)

Several families tell other stories of efforts to assist their child to develop some relationships beyond the family. Unfortunately most of these efforts have not been particularly successful.

> His sister occasionally brings friends home from school. They live in a sparsely populated area, so access is difficult. Sometimes Mom will invite

> school friends for a party. Last year the superintendent cancelled a party in John's home at the last moment.
> The community they live in is not too accepting. The ARC organizes recreation only for children who are mildly retarded. They have not done anything for more involved children.(22)

In almost every case the families interaction with the community is dominated by a sense of being the outsider. When this is linked to the extensive demands which are associated with the care of their children it is little wonder that the parents are not more aggressive in trying to connect with their communities.

> Mom has a couple of neighbors who will at times come over, even with gifts. Mom feels uncomfortable and out of place because she has been there for 3 years and people didn't acknowledge her existence. Mom is Hispanic and with a disabled child. Didn't feel accepted. It would be hard for Mom to even take Pam across the street to the park because she disliked the way people would just stare at her and Pam. There would be times when they would make ignorant remarks and Mom would just rather not take her to the park and have to listen to these comments.(34)

> I can't get involved in the community because I must be home with Star, unless I have someone to watch over her. The community doesn't understand Star, they just look at her. (42)

Financing Home Care

Because of the significant expenses associated with the needs of their child and the limited resources available from many traditional insurance carriers the majority of the families (69%) are covered by Medicaid. Factors related to the need to retain eligibility for this program are consistently reported as a major concern of the family. This contributes to the degree to which the family's life style is determined by the care needs of the child. They are not just effected by the demands and the out of pocket cost of care , but they must also keep the family income at a certain level, less they become ineligible and so lose the much needed medicaid coverage.

While the majority of the families are covered by Medicaid about 60% also use some type of private insurance to meet the expenses of their child's care. About 21% of the families receive Social Security benefits. In addition to expenses covered by insurers, 42% report major out of pocket expenditures related to the care of their child. It is worth noting that 27% of the children have been without any health insurance coverage at sometime.

Table 10 provides a summary of the families' experience in filling claims against their medical insurance carrier. All in all, 54% of the respondents report that they are not satisfied with the quality of their medical insurance coverage. In most case this dissatisfaction seems to be associated with the carrier's denial of claims for a service which will support them in their efforts to care for their child at home. This irritation is directed at both public and private insurers. As the last column in Table 10 shows about 40% of the families reported that significant aspects of home care were not covered by their insurance.

In the interviews it soon becomes clear that even with extensive insurance coverage for the expenses associated with providing home care many families experience additional major household expenditures which increase the financial pressure on them. A number of examples of these expenditures follow.

> Installed chair lift on stairs--too heavy to carry as he cannot walk. Diapers, formula, kangaroo pumps, tubes, gauges and we purchased the van for $21,500.(01)

> Driveway costs around $5000.00. Electrical wiring $500.00--Ryan's room is on a separate box. Electric bill, gas bill, phone bill--nurses make long distance calls.(03)

> John is a paraplegic and is "dead weight" - Mom is only 5 feet tall. He can only be made mobile with the assistance of 1-2 adults - cannot turn from stomach to back. They use a crane system to help move John. He is getting too big for current system but family has to build on to their house to accommodate the larger system.(22)

> A) Auto air conditioner $900 installed last week. B) Adaptations to Pete's room to accommodate extensive supplies and equipment. C) Shelving and drawer space $600. D) Air conditioner Pete's bedroom $400. E) Intercom for Pete's room $60. F) Special bed built for Pete with 2 large deep drawers to store emergency tray, amby bag, suction pump, catheters. This permits immediate access to these. G) Ion air purifier $70 (asthma). H) Electrical wiring in Pete's room to accommodate equipment and separate fuse installed for life support equipment $550. We also saw a dramatic increase in bills for electricity due to equipment use and to constant use of air conditioner and oxyconcentrator.(38)

For some of the families expenses of the type just listed appear to be a luxury because of their lack of medical insurance coverage. For these families meeting basic medical costs pushes them to the fiscal limits

> Star has no Medicaid or SSI. So, Mom pays for Pampers - $90.00 a case, Nutrmegin milk - 2 cans a week / $16.00 a can, Bibs, towels, baby powder and constant changes of clothing - $300.00 for the summer. She couldn't get stipend, so she paid $400.00 for camp. In addition all Medical appointments must be paid for GP ($21.00 a visit), Transportation to appointments ($16.00 a visit), Neurologist ($21.00 a visit), Dental ($30.00 a visit) and Star has outgrown braces -- her heels are bleeding. She

> desperately needs new braces but there is no coverage. They would cost $2,000.00.(42)

A major problem which many families encounter is lack of complete information about what their insurance will cover.

> Parents were sent out to a research center which specializes in the child's rare disorder. Parents were not told they would have to cover certain costs or that insurance wouldn't cover certain research needs. Parents received bills for up to $7,000. It was left in parent's hands. Through putting bills through insurance agencies over and over, half of the bills have been covered. They are awaiting word from insurance company as to who will be covering the rest.(43)

A universal issue appears to be the drawn out process of payment to home care providers. Almost every family in the study group tell of the trouble they had obtaining or retaining services simply because the providers must wait so long to be paid.

> All insures have delayed payments. The enrollment process was a mess and not well defined. The bills are lagging in payment to providers which carries an interruption and lack of nursing services.
>
> The billing process takes so long that many nurses have left the case. Nurses notes must be sent 1st to Medicaid then additionally to PHCP. They must photo copy (at their expense) 2 sets of notes to submit to PHCP even though the allowed financial amounts are known. Mom feels like she is jumping through hoops.(31)

When this slow payment and lack of information is further complicated by the bureaucratic maze which seems to confront these families, parents can find themselves without services even when they have done everything they are supposed to.

> The major medical is slow to reimburse. The nurses won't work for Medicaid because it takes them too long to get paid. St. Joseph's is the community case manager. Billy was hospitalized for two weeks in the winter, and home care services can only be reimbursed through BC/BS ("through a N.Y. State licensed home care provider") if Mom contacts St.

> Joseph's upon discharge. Mom called the day of discharge to let them know that Billy was home; they acknowledged this and took a message. Mom doesn't remember who she spoke to but thought nothing of it. She then received a bill for $15,000.00 for home care services because they were not under BC/BS. Mom called St. Joseph's to inquire about the billing and was told that BC/BS could not be billed for services (equipment and supplies) unless St. Joseph's was informed about Billy being home. Mom told St. Joseph's that she had called but they didn't believe her. Mom also called BC/BS to see if they would help her. BC/BS said that they had to be notified within 24 hours of discharge to approve payment, but would assist if St. Joseph's wrote them a letter describing the 'mitigating circumstances.' Mom called St. Joseph's and asked them to write a letter to this effect but they refused. So she really feels that they do not care. She phoned around and found out that most providers which accept children have the same attitudinal 'disgustingness.'(05)

In an effort to avoid these problems some of the families take the path of least resistance. Of course many parents cannot afford to take this approach to expediting matters.

> Mom gets small bills here and there. She gives the provider the insurance information. It becomes a 3-ring circus where she keeps getting billed afterward so she becomes frustrated and will pay some of these out of her pocket just so that the nonsense stops.(41)

When some of these families have been forced to the end of their fiscal rope because of the care needs of a child, mere survival demands that they develop expertise in "gaming" the system.

> All savings were gone. We had to hide money. I was an RN but I had to work as a waitress off the books to make ends meet. You just don't make it on SSI and food stamps. Lot of difficulty with doctors. The doctors have refused services because she has Medicaid. Had to trick doctors to get the services and then tell the doctor that he had Medicaid. Otherwise they wouldn't help us.(48)

Indeed it is surprising that these parents are not more cynical, particularly in their dealings with the Medicaid system as they are daily exposed to arbitrary, apparently capricious decisions, accompanied by seemingly irrational regulation.

> Medicaid would only approve 1 box of Pampers per month. Mom would get the rest needed at $55.00 per box.(44)

> Dad says that reimbursements and the way they are handled is weird. For example, Pampers are less expensive than Depend diapers. Stanley is 4 years old. Why not have him use the Pampers -- Depends are more expensive. But Medicaid will approve the Depends Adult Diapers instead of the Pampers.(47)

One of the most frustrating experiences which these families share is the lack of responsiveness of professionals and insurers to their assessment of the supports that are needed to adequately care for their children.

> Morris needs to be watched constantly, because if he goes to sleep he will arrest. Lisset has been asking for an adaptive stroller for him for almost a year now so that she can bring the vent if he falls asleep. She wants the family to be more mobile. . You have to take a crash bag along whenever they go out. Nothing has happened. (04)

> Medicaid will only cover certain things, not necessarily what the doctor recommends or what she feels is necessary. For example a walker is desired, but physician will not prescribe it, and suction is used to remove seizure-causing mucous from his lungs, yet the physician will not prescribe a machine for their home either.(13)

As in so many of their other dealings with people who they had previously regarded as knowledgeable professionals these families soon find that case managers and benefits coordinators are woefully misinformed about necessary coverage and basic procedures. This experience is so universal and recurs so frequently among these parents it is little wonder that they begin to see an organized threat to the welfare of their child and family.

> The family is about to experience insurance burnout because they pay high rates and were not informed of lower-cost services. They were misinformed about the services they were eligible for and had to do most of the paperwork themselves. After the county case manager tried to force the family to pay for additional expenses, SKIP intervened and helped negotiate a solution by which the insurers take care of the costs. On several other

> occasions the state has misinformed them or tried to take away or scale back their services. This has made the family suspicious of the state.(08)

At times the actions of some insurers seem to affirm these suspicions as families see themselves as targeted for loss of benefits after their costs have exceeded some apparently predetermined ceiling of acceptable risk.

> Insurance company is giving family problems; coverage is pending review. Family will find out in a few weeks if son will be covered. Father was laid off from work for two months and insurance company is using this and the baby's pre-existing conditions as possible reasons for denying their claims. (10)

> Dad was covered with ***unlimited*** insurance through the workplace. Major medical was covered by Travelers with no cap. He felt, from an insurance perspective, that all bases were covered. In January of this year he was told that the employer would become self insured and there would be new restrictions placed on services. Nursing would be capped at $50,000 per year per client and that HMCO pay would be tripled. He got this information on Jan. 15, and shared it with SKIP and his Nursing agency and the DME providers.
> Under NY state Insurance law this is not legal. The primary carrier must remain intact for a minimum of 365 days on pre-existing conditions until the new insurer can assume the case. The family was devastated and about 200 hours of advocacy had to be devoted to assuring that the Union and Pension Welfare Fund complied with the state regulations. Because the care supports were withdrawn due to lack of funds, Sissy also had to spend 30 days in the hospital to meet the model waiver requirements, so that the nursing hours could be paid for while the insurance battles were being decided.
> The family also had to have an outside attorney because Dad was getting a lot of pressure from the Union. He felt that it was based on the medical cost of Sissy to the Welfare Fund. He also went to the newspapers with the story and he felt like his job would be in danger if he did not get legal advice. His employers have tried to change his work schedule on several occasions.(18)

Even when the family is able to negotiate some form of coverage which seems to adequately meet their needs, they often find that it is a real battle to assure that cost control does not take precedent over quality care.

> Getting nursing has always been very difficult because the insurance company obligated the family through an exception to policy to use their

> home care team. This team is a subsidiary of BC/BS and run out of the hospital. The family feels that these burgeoning agencies represent a conflict of interest because the payer is the manager is the monitor is the provider. They felt this most acutely when they were trying to negotiate direct insurance payment for the nurses. They wanted to hire the nurses directly to avoid the agency overhead and pay comparable salaries to the ICU so that they could get ICU staff. The insurer refused and after an unskilled nurse who was caring for Jim almost caused him irreparable damage the family threatened to start legal action. The rates were slightly increased and only R.N.'s are on the case, but the shifts are rarely filled and they have some well-trained nurses, but the pay does not attract the ICU staff. The family has to put a great deal into training new nurses, and the turnover is high.(20)

Pete mother, who as a registered nurse has some experience with the working of the health care system, offers one possible analysis of the root cause of the problems which so many of the families encounter in their dealings with Medicaid and private insurers.

> This home care program was unprepared to deal with the wide scope of care a child like Pete requires. They consider chronically ill children as those in need of a wheelchair or a walker, but not the expensive equipment supplies, meds and other care related expenses incurred by Pete. They illegally withheld payments in violation of signed contract for a 5 month period and for several shorter periods after that time. (38)

TABLE 10
INSURANCE COVERAGE OF SERVICES

Percent Of Households Indicating That		
Service	*Was Covered*	*Was Not Covered*
HOSPITALIZATION	87.50%	
DURABLE MEDICAL EQUIP.	85.42%	10.42%
MEDICATION	81.25%	10.42%
PHYSICIAN VISITS	81.25%	4.17%
MEDICAL PROCEDURES	79.17%	2.08%
HOME CARE (NURSING, ETC.)	60.42%	39.58%
SPECIALIST CONSULTATION	50.00%	8.33%
EQUIPMENT MAINTENANCE	50.00%	
HABILITATIVE TREATMENTS	47.92%	6.25%
DIAPERS	41.67%	16.67%
TRANSPORTATION	41.67%	16.67%
ADAPTIVE EQUIPMENT	41.67%	6.25%
SPECIALIZED DIETS	20.83%	8.33%
OTHER	10.42%	16.67%
OUT OF TOWN TRAVEL	10.42%	
HOME/VEHICLE MODIFICATION	6.25%	6.25%

Services to the Child

In the survey questions we asked the families to synthesize their experience in dealing with the various services that impinge on the live of their child and family. In this inquiry an effort was made to differentiate services which were intended to primarily meet the care needs of the child and those which supported the family in its roles as a family and caregivers. For the most part this distinction worked quite well. The exceptions being those services which were identified as service coordination, discharge planning, or case management. In the discussion which follows an effort has been made to distinguish those case coordination efforts which focus almost exclusively on obtaining services for the child from those, such as SKIP, which have a broader perspective on the child within the context of the family.

Table 11 presents the range of services received by the children in the study group. Most of the children are receiving services from multiple providers and multiple systems. In fact 70% of the children receive services within the home from 5 or more providers. It is instructive and a bit disconcerting that although they are at the center of very complex service networks only a total of 45.8% of the families receive case management or service coordination services from sources other than SKIP. This absence of support in the area of service coordination is doubly underscored when the interviews reveal that much of the service provided under this heading is neither a service nor supportive.

Many of the families have stories of very positive interactions with individual therapists and physicians who have known them and their children for a long time. These providers have acted as major sources of support and advocates within the system. These same individual professionals develop a real responsiveness to the unique characteristics of these families and attempt to provide truly individualized family-centered services. For example Pete's pediatrician is very sensitive to his fear of hospitals and so provides that unheard of service--the house call.

> As far as visits to the hospital, doctor's office or outpatient clinic go, Pete's pediatrician sees him at home except for regular well child care. Pete's condition is often too unstable to transport him safely by car, but he responds well to treatment and has not required hospitalization since discharge. Pete's pediatrician spends a great deal of time at our house. That may be because the pediatrician has been attached to Pete since 6 months of age. He provides his services free of charge because of his emotional involvement with Pete. This also makes him willing to invest special time and attention a child like Pete requires. I shudder to think of the potentially harmful physical and emotional effects there would be for Pete if we had to transport him by ambulance to a hospital ER each time he required medical attention in an emergency. After spending 4.5 years in a peds ICU Pete's biggest fear is having to return to hospital. Clinic and dental visits cause sleep and behavioral changes for weeks afterwards. Fortunately as an ICU nurse (with long peds experience) who is lucky enough to have a pediatrician willing to extend himself in order to treat Pete at home, I am able to prevent Pete from having to live his nightmare (at least so far).(38)

Unfortunately these good stories are balanced by many more instances of "detached" professional behavior or, worse, professional providers who at least in the parents perception come across as callous.

> The MD is still not up-front with the family. Mom feels that he does not respond to Mom, whereas, if Dad gets involved they get the answers they need.(03)

> There have been problems with equipment failure. The ventilator stopped working, and no nurses were there to take care of the problem until Dad noticed the situation. Often the nurses fail to change the baby and she is left wet and unattended. (09)

> Sally's care has been inconsistent. There is a lack of communication between Mom and staff. There has been improper supervision and non-observation; Sally is constantly dirty and Mom cleans her all the time. Mom feels it is frustrating to deal with these issues on a daily basis.(15)

Over and above these situations which appear neglectful, many parents recount incidents in which "active treatment" seemed misinformed and in which their understanding of the child was ignored.

> Barbara is now weaned from the vent after many years and although she will always have C.F. she is decanulated and really does much better, but has some eating disorder. During her prolonged hospitalization, they force-fed Barbara. The parents objected and tried to fight this method. They were told that they could not take her home unless they got a certain amount of calories into her per day. Barbara vomited at every meal and mealtime was a horror. The parents are now seeing a behavioral psychologist for Barbara. If they had it to do again they would never listen to the physicians. This is their only regret. Barbara is slowly doing better with food intake but it will take a while to get over the "punishment of what the doctors prescribed."
>
> The other battles were associated with weaning Barbara from support systems. The family was reluctant to go forward quickly because she had so many setbacks. The doctors would not listen and she got very sick twice and wound up back in the ICU on full life support. When Barbara improved the family took her home and weaned her without listening to the doctors and Barbara is now decanulated and going to school.(19)

It is little wonder that as the care of the child becomes much more subtle the parents are less and less inclined to put complete trust in professionals.

> Mom feels that the tricky part of caring for Sissy is deceptive to the eyes she just looks so "cute" and well that often new staff do not understand the importance of monitoring her well. Dad feels that it is easy to get sloppy with Sissy and that is how you can really lose ground.
>
> Dad: "You cannot wait for her to collapse before you react. The strain of her care is much more dramatic because it requires so much judgement and observation. Weaning her from the system requires that staff have a total overview of her baseline status."(18)

These citations from the interviews create the illusion that only medical services to the child are misdirected. This perception is rooted in the fact that the medical system plays such a large role in the lives of these families. The facts are that similar incidents seem to occur whenever the families encounter professionals who are narrowly focused on preserving their own turf.

> Charlene was in a school program this year. She loved to go to school, but the teacher was dangerous. For example, while Mom was visiting her classroom Charlene was squirreling some egg salad in her mouth and the teacher tried to forcibly get it out with a plastic spoon. Mom tried to talk with the superintendent of schools. The superintendent met with Mom and SKIP and asked that Mom keep Charlene out of school to help him get rid of teacher. This would strengthen his position. He "smoozed" Mom and SKIP into thinking that his intent was honest and sincere.
> Mom did keep Charlene out of school and as a result the classroom in the local school where Charlene had been attending was shut down. (21)

George's school experience hints that such contradictory behavior on the part of professionals demonstrates that they are more in tune with some of the misperceptions held by the uninformed general public than they are with the state of the art in best practice regarding services to children with specialized needs.

> George's teacher once gave his class a lecture on Muscular Dystrophy saying to a full class how George would be dead by age 20. He felt badly for other peers but is full of hope and inspiration for others. Mom has fought all types of battles. The most receptive was the principal of the local elementary school who made all the necessary accommodations, but once George hit special ed. things became complex and went down hill. (23)

TABLE 11:
SERVICES RECEIVED BY CHILDREN WITH SPECIALIZED NEEDS IN STUDY GROUP

SERVICE	*PERCENT OF CHILDREN RECEIVING SERVICE*
PHYSICAL THERAPY	72.92%
SCHOOL	66.67%
EQUIPMENT MAINTENANCE	50.00%
HOME NURSING	43.75%
TRANSPORTATION	39.58%
SPEECH THERAPY	35.42%
CASE MANAGEMENT	33.33%
DISCHARGE PLANNING	22.92%
OCCUPATIONAL THERAPY	22.92%
OUTPATIENT MEDICAL	22.92%
DENTAL CARE	20.83%
INPATIENT MEDICAL	18.75%
RESPIRATORY THERAPY	18.75%
OTHER	14.58%
HOME HEALTH AIDE	10.42%
VISION CARE	10.42%
LIFE SUPPORT EQUIP.	6.25%
RECREATION ACTIVITY	6.25%
COUNSELING	4.17%
OTHER SPECIALIZED THERAPY	4.17%
ADAPTIVE EQUIP.	2.08%
BEHAVIORAL THERAPY	2.08%
TOY LENDING LIBRARY	2.08%
VOCATIONAL/PRE-VOCATIONAL	2.08%

Family Supports

Table 12 summarizes the range of services which fell under the broad umbrella of "family supports" rather than clinical services for the child with special needs. Missing from this table is the SKIP case management services in which all of the families in this study participated. The families involvement with SKIP is summarized in the next section of this report.

When the services in Table 12 are compared with the range of supports listed as the components of a comprehensive system of family supports (e.g. Agosta, 1989; Taylor, Knoll, Lehr, & Walker, 1989) one is impressed by the very limited array of support services actually accessed by these families. This fact is further underscored when we realize that 38% of all family support services in the study group are represented by membership in traditional parent advocacy organizations such as the Association for Retarded Citizen, The Autism Society, and so forth (parent network, newsletter, parent instruction, parent advocacy/training). In addition, the majority (62%) of families indicate the only real support service they are receiving is provided through their involvement with SKIP.

When we turn to the information obtained through the interviews the absence of true "Family Support" except as provided by SKIP is further underscored. The responses to inquiries in this area highlight the need for specific support services and the anything but supportive interaction which many of these families have had with some of their family support workers.

The experience and needs articulated by many of these families indicate that while the system has, to a certain extent, been able to respond to some of the child's highly specialized needs, it has not addressed some basic supports that are currently available to families of less seriously involved children.

> We need respite--time when Mom and Dad can be together to rest, relax and go out. Grandparents could baby-sit at one time but son's care needs are becoming more intense--he has grown too large for them to move him.(01)

The inadequacy of professional and paraprofessional preparation is underscored by the frequency with which families encounter providers who are completely out-of-touch with the idea of community-based, family-centered care.

> Mom was not completely trained in the hospital. She also went home with a service provider (the hospital-based home health provider) that made many promises initially as case managers. They did not understand community-based care and were full of opinions. They were more interested in making Mom compliant than providing support. When the family decided to bring Gini home they were discouraged at every turn. One social worker even went so far as trying to have the child taken by Bureau of Child Welfare and placed. After a great deal of effort this endeavor was stopped and the hospital administrators were apprised of this situation. The social worker was taken off the case and plans were developed to bring Gini home with the full range of services. The 'insulting' professional behavior continued, however, and it extended to the hospital's home care division. A nurse who supposedly served as case manager did not know how to obtain many of the necessary nursing services for Gini and so took a great deal of additional time to arrange the services. As a result Gini was in about two extra months. The hospital homecare services/case management were dropped and things are going much better.(02)

Often the root of the problem can be traced to the complete lack of on-going communication and effective services coordination.

> Case manager from state OMR/DD does not keep in contact with the family and is not aware of what's going on.(11)

> When she was an infant Mom had 24 hr feeding duty because she was tiny and frail. The hospital team explained nothing and Mom was totally unaware of the needs and the long-term unending demands. She was sent home without any services.(21)

Most of what passes for discharge planning seems to put little more effort in preparing for the discharge of these very complex children than is done for a young adult returning home after minor surgery. This lack of support is often accompanied by a clearly stated judgement that the family's decision to take the child home is not valued. Indeed, some families finds themselves abused in the name of service planning.

> Discharge planning was a mad house. All the equipment, everything was arriving at the same time as Eva did. We didn't know what to do. Everything was chaos. Two nurses came home with the child. From there on in I would have to wait for nurses. Many times they wouldn't arrive at all.
> I was never told I could have a homemaker. The social worker who was supposed to have planned everything did not. She would make me cry. She said things like "benefits would be denied, " or "You have no right to welfare."
> The discharge planner in the hospital social service department told me that I would never be able to take my child home, that I wouldn't be able to care for her at home. Did terrible job. Any confidential information she would write down in book and later expose it. I trusted her because she was the social worker and she treated me badly and disrespected me by writing the personal things I would tell her. (44)

Given this experience it should be little wonder that many of these families, especially those from minority groups, are looking over their shoulders to see the state threatening the integrity of their family.

> Mom is very concerned. Is convinced that someone will take her child away. Did not answer too many questions. I would like to probe a little bit more. She was very concerned that this information will be used to take Sukari away from her. She is frightened of revealing anything. She was originally concerned about even answering a couple of questions on this interview.(32)

Most families find themselves being looked to be masters of a system which is totally new to them. They are called on to devote their energies not to being a parent but to being a service manager. By implication if a parent can master this coordination game then they must be good parents and therefore merit preferential treatment.

> Mom is an R.N and the primary thing that she was told was "Thank GOD you are an R.N". There was no training, no referral to resources and no information. Mom is her own best advocate and as a result receives preferential treatment for accessing services. Mom must recruit, train, and provide quality assurance. Payments, bookkeeping, submission of vouchers, and prior approval are also dependant upon Mom. (25)

TABLE 12: FAMILY SUPPORT SERVICES RECEIVED BY MEMBERS OF STUDY GROUP

SERVICE	*PERCENT OF FAMILIES RECEIVING SERVICE*
PARENT NETWORK	20.83%
COUNSELING	16.67%
SERVICE COORDINATION	12.50%
HOMEMAKER	10.42%
RESPITE	10.42%
TRANSPORTATION	10.42%
NEWSLETTER	8.33%
PARENT INSTRUCTION	8.33%
FINANCIAL ASSISTANCE	6.25%
OTHER	6.25%
PARENT ADVOCACY/TRAINING	6.25%

Effectiveness of SKIP Case Management

As far as many of the families are concerned the only "service" they have received that can appropriately be called "Family Support" has been their involvement with SKIP. As we saw in the previous section many of the other organizations and professionals involved in their lives have approached families either as the all knowing professional or the fraud investigator who was out to insure that they did not defraud the state, the insurance company, or the provider. Only in their interaction with SKIP do the family consistently feel they are being treated as equal partners collaborating in seeking the best interest of their child. From SKIP they received assistance in working through the maze of information about support services and payment mechanisms in an effort to insure that the child and the family got the supports they needed.

The answers to the survey questions clearly demonstrate that the families see SKIP and the case management service as a valuable asset. They consistently indicated they were very satisfied with SKIP and its services were very valuable to the family. From the interviews it is clear that in some cases the families would have not been able to maintain their children at home without SKIP. In other instances SKIP has made the difference in obtaining services, receiving insurance coverage, assuring services met minimal standards of quality, and preventing vendors from over charging. All of this was achieved in a supportive atmosphere which is so different from the families' experience with some of the case managers and discharge planners described above.

The experience of Lucy's family captures something of this phenomena. They have a case manager and a discharge planner and yet the only organization which is responding to them is SKIP.

> If it wasn't for SKIP they would never have known how to get her home. Mom and Dad also do not understand why SKIP is doing all of the tracking of the discharge plan, when they are supposed to have case management, through the care at home (model waiver) program. They do not understand why SKIP is the only group that seems to care if Lucy lives at home. The case management team lost two sets of eligibility papers. The hospital is putting a lot of pressure on the family to place Lucy because they want the bed. Mom and Dad feel like they have four providers, hospital, case management, equipment folks, and SKIP. Only SKIP converses with all of the others. There was a four month confusion over the eligibility requirements (model waiver and medicaid) for the county because the case management team is two counties away. The family feels like ten people are asking them very involved questions. SKIP is the only group that explains the reason behind the questions. Lucy isn't even home as yet and 11 people have been to their home. The equipment company has taken 6 weeks to complete a list of needed supplies and the cost. The nurses have not even been located to provide the services in the community. The parents have not been fully trained so when funding is finally secured the case management team and discharge planners will need to spend additional time resolving these issues.(27)

Perhaps one of SKIP's greatest strengths lies in its independence. It is able to look to the best interest of the child and family, knows the system, and is willing to do the leg work needed to build a case for private insurers or state funders. In this regard it captures the essence of the ideal of independent case management.

> The family first contacted SKIP many years ago because they wanted to bring their son home. He had been in the hospital for 6 months and they wanted their family reunited. The hospital was in favor of this but they had tried everything and were not successful. SKIP negotiated an exception to the family's insurance policy to allow for the hospital-based dollars to be applied to home care. This was underwritten by Blue Cross and Blue Shield. All of the data was collected by SKIP and Mom feels that if the "pressure to do this did not come from the outside" Jim would still be in the hospital.(20)

In a similar vein SKIP's independence has enabled it to look over the shoulders of many of the other actors involved in the lives of these families and assure they do not violate any basic rights.

> Mom feels that SKIP monitored discharge planning process and aborted unnecessary screw-ups, omissions, and mis-information. SKIP also got the family's insurance reinstated because the family was not presented with the option to self carry as per COBRA. The insurer violated law. Mom feels that only SKIP would have assisted them with an issue like this.(31)

Often the SKIP role entails affirming the parents' instincts, particularly when they run into non-responsive professionals. This level of support, when everyone else seems to be on the opposite side of an issue, may be the single most valuable contribution SKIP makes to these families.

> Ryan's birth was a horrible experience for the family. Lots of trouble with the doctor. Ryan spent five months in the hospital. Mom wanted to understand what was going on, and wanted Ryan to see a specialist in Boston. The hospital "blew up". The MD and the family had many fights. When the family wanted to transfer Ryan home, the MD could not assure that he would maintain the same level of coverage. Mom was hysterical and called nurses who assured her that Ryan would be safe. She was afraid to make waves because she felt as if her daughter were being held hostage. The home care company was very helpful. The family was never told about any entitlement programs. The hospital made many service provider decisions without consulting the family. The hospital linked the family to the most expensive providers and the family was about to reach the annual cap so the family decided to direct hire and agency sued them. When Mom presses MDs for answers, they tell her to seek counseling. She is relieved to know that she is right to ask the questions she is asking and that SKIP would help her get her questions answered.(03)

This oversight on the providers and insurers becomes increasingly significant when we realize that most of the families in this group have shared experiences in which a professional failed to provide some basic information.

> Mom was also entitled to have her son covered by the Care at Home Program. Her son met all the criteria to be part of this program with the exception of not having applied for it while still in the hospital. The hospital's social worker had failed to inform parents about this program and discharged the son from the hospital. SKIP arranged for a fair hearing

> for the family. At the hearing it was determined that the son met all the criteria with the exception of applying in the hospital and was turned down. We put Mom in touch with the N.Y. Lawyer's for Public Interest who is working with SKIP in bringing this matter to the courts. He feels if we can set a precedent it will also benefit all other families who lost out on waivers because they were not informed or failed to apply in the hospital. Case is pending Mom's decision to go ahead with the court case. Mom is very angry that the state is making it so difficult for her son to get into a program for which he meets all the criteria. (01)

The key to much of what SKIP does seems to be rooted in an attitude of working with parents by providing information, support, and critical feedback, rather than trying to manage them.

> Mom likes to be independent. She appreciates that her case advocate helps her to "run" things and does not try to "social work" her. She likes to do her own thing and is glad that SKIP supports those efforts. She feels more control that way. She also said that SKIP was very reasonable when she had no place to turn and called on week-ends, that SKIP didn't always agree with her expectations of providers, but at least SKIP always had a nice way of letting her know. She said the most important thing was that SKIP was on her side, and even though she was skeptical and unsure because we were a new organization we always gave her very accurate information.

In sum, the families really feel that the SKIP program is the one mode of service on which they can consistently rely.

> I would have gone under. SKIP got me nursing when I needed help. They followed through and found me an agency and got my prior approval in order. If I had to force the social worker to do something I would have collapsed. Nobody knows this care and what it takes until they walk this path. I cannot say enough or thank you enough.(04)

> We could never have gotten Margie home without SKIP. I will never forget when Margie arrested at home - if SKIP had not made us organize all the emergency equipment she would have died. We also are not as expensive because of what SKIP did with the equipment providers and so the premiums (self pay) are slightly less.(17)

The Families' View of the Future

> Doesn't look long term--living day by day. (01)

The future is a difficult issue for many of these families. The major traumas they have thus far endured in the form of the child's disability, the constant battle to obtain support services, the financial strains, the re-ordering of their social world, and most of all the day-after-day care needs of their children have led them to adopt a perspective which takes life one day at a time.

This "live for today" attitude, which is consistently reported throughout the interviews, is further reinforced by the big question marks in future of all of these families. First, the parents of children with degenerative or terminal conditions, while not denying this reality, consciously chose not to dwell on it and to devote their physical and psychological energy to making the most of the present moment.

> She wants to make the rest of Pat's life as happy as possible. She saw a twelve year old boy recently with Pat's disease and this gave her hope that Pat will live for a long time, especially considering the fact that she was told in the beginning that Pat would be a vegetable all his life.(14)

Second, families of children who will need life long supports also share this attitude. In these cases, we get a sense that not thinking about the future is one way for the parents to conserve their energies for the battles yet to be fought. Essentially they are very aware of the struggles they have fought thus far. They are leaving concern for the future struggle for life-long services to a time when they must confront that issue.

> "Stop punishing parents for keeping their children at home." Mom feels that she has been told about 80 times that all of this would be less stressful

> if she would just place George. They've won battles for George but were so disgusted that they felt they didn't win.
> Mom is drained. Parents have to fight because others do not. "Since my husband was in the hospital 3 years ago, not a day goes by that I don't wonder what would happen to George if anything happened to my husband. This must make us the smallest minority in the world: Parents who think, 'Please God, let him go before us.'"(23)

When we ask parents to give us their view of the future some of them did articulate an image of the changes they would need to see in the current system of adult services, in order for them to feel secure about the future of their child.

> Mom would like to see a life-long IEP program with extra services for those over 21 and group homes for people with similar needs as her daughter.
> Mom is afraid of what will happen to her daughter when she is gone. She would like to see more group homes formed for people with her daughter's disability.
> Daughter should be raised in a loving environment. Too much money is being spent on institutions such as...(the local Mental Retardation Institution)..., which is a "hellhole." The money should be spent instead on home care and innovative programs for children with special needs.(12)

All of the concerns that flow out when one mother turns her attention to the future of her daughter should make it clear why many of these families chose not to deal with the future.

> I am terrified. She deserves comfort and security and she deserves to learn and live in a supportive environment. But all of this depends on income. Utopia does not exist but even the simple practical things I want for her do not exist and there is a constant battle to get the smallest things.
>
> How to face puberty? How can we find skilled people who really care? Where is a medical system that can truly be responsive? Are there alternatives to the lousy group homes or the "hell holes" of institutions ? There is a natural phenomenon of a child leaving the nest - but what I've seen are dumping grounds. This is the most neglected minority group known to man.
>
> The reality of it is nobody cares. Those Hollywood images of caring people is a fantasy. Why do people work to save lives and then give up on children once they are saved...this is a horrible question to ask about such a sweet child.
>
> There is a great deal of shame when we look at what conditions exist.

> Nobody should have to confront these inhumane service providers. Nobody really cares that Charlene can learn and hasn't learned to her capacity. The entire issue raises morality issues beyond simple answers. The lack of support makes a parent weigh the "value" of their child's life and that is so fundamentally wrong.(21)

This question leads Pete's mother to reflect on the fact that what she would regard as an acceptable future for Pete demands some fundamental changes not in the system of services but in our society's basic attitudes to people with significant disabilities. She found these attitudes expressed in the artificial limits which our culture places on the ability of these people to achieve their full potential.

> I can't bear to think about the future (if Pete was not disabled his prospects would be wonderful) Pete is a great kid, he works hard and is talented as an artist, and academically (Pete scored second in class of 30 normal kids in a standardized Stanford achievement test, his scores were in the 97-99% in all areas at the end of his first grade). His aspirations are tremendous, he will undoubtedly have much to contribute to society, if he ever gets the chance. Realistically I doubt that Pete will get the chance in our present society. If he does what will it cost him in lost medicaid coverage? Will he be able to pursue a career?
>
> One of my chief sources of stress is what will happen to Pete when I am gone. If money or property is left to Pete he will probably loose medicaid coverage. Then what?. Who will advocate for him and protect him? Who will assure that he is cared for? Is this bright, funny, loving little boy doomed to live on welfare? Or will he choose not to continue living at all when He finally realizes that his hard work and achievements are all for naught? I hope that by the time Pete reaches adulthood, our society will provide him with other choices, like being a contributing functioning member of the community who can use his skills to remain self sufficient without losing medical services and care he needs.
>
> It is traditional in our country for parents to work hard in an effort to help their children attain a better position in life. Most parents promote the best opportunities for growth and learning in an effort to help their children develop. When parents die their children are usually left with the benefits of parents hard work. Why is a disabled child not entitled to this? Why must he choose between the health care he needs to survive and a decent home to live in or the self esteem that comes from self sufficiency and earning a living at a challenging job which allows him to use his exceptional talents? (38)

Crucial Issues

What is consistent in the interviews is a theme that the care of the child with a disability is worthwhile. Most parents don't see the demands of care as a "burden"--it is part of being a parent and loving a child. What they consistently identify as their burden is the continual struggles they most go through to get the supports they need to appropriately care for their child. In this regard they all see SKIP and the case management services as a valuable asset which helps them to wage and win some of the battles they have, in some cases, been fighting for years.

For example, George's parents told the interviewer the system can really wear you down, even if you are used to being the pioneer. This sense of frustration can become intensified, if the battles continue even after years of effort, particularly as the family is confronted with a progressive degenerative disorder.

> Mom told the interviewer, "You know, I am so tired of being a pioneer. I fought for accessible school busses, we got George into the accelerated classrooms, we were in court for the first five years (after diagnosis), more than we were at home. I just want to follow for now because my son is failing and I want this time to be special and uncomplicated."
> Mom feels that George will need nursing eventually and that will really be a lot of traffic in the home - so she wants quiet and calm time.(23)

Although families like George's have been fighting these battles for years, younger families like Jim, today, have to fight some of the same battles.

> Mom: "I do not understand why they fight us tooth and nail for every little thing and would not ask us a single question if we left and abandoned him to an institution. Our newest battle is now the school system. We are now in court at great expense to our family so that Jim can get the nursing he needs at school. I am a little tired of being a pioneer. We are fighting like this to get him into BOCES- can you imagine what it is going to be like to get him into elementary school?"
> Dad sits on a lot of statewide coalitions and even with his visibility things are a struggle. Both parents are tired and would love to go back to just being a family.(20)

Another consistent finding in this area is frustration and, in many cases, anger over the incredible lengths these families have had to go to in order to get even minimal support and assistance in their efforts to care for their child at home. What is very disturbing in reading the interviews is the arbitrary manner in which the state, health care providers, local education authorities, insurance companies, and home care providers deal with these families. Again and again the families report being treated as if they were trying to steal something from these individuals and agencies which are supposedly there to offer assistance to them. Little wonder that many of the so-called helpers are seem as the families' major problem.

Again George's family with their years of experience are quite articulate in identifying some basic issues which some of the younger families are only beginning to confront.

> She told the staff at SKIP "It isn't the child or young person that makes you crazy -- it is the system."
>
> Mom told the staff that all she needed was an extra set of hands so that Dad could go to work and she could get a break. Mom especially does not understand why just a little support is so hard to come by. She feels that just caring for a progressively ill child is enough stress -- she wants to understand why it is further complicated. She also doesn't understand why the social workers at the hospital for the past 17 years have not connected her up with some kind of supports. Mom and Dad feel that they have too many clients to really do anything for individuals.
>
> The PHCP paperwork for billing had to be completed and sent back to PHCP by the social worker at the University clinic to start payment for the home health care agency, this process was so delayed that the family almost lost their services.
>
> Dad does not understand why SKIP had to intervene to get these issues resolved.
>
> "Why are our services always dependent on the good will of a particular social worker when the family assumes they are doing their job?"
>
> Dad wants to understand why you have to monitor people that are supposed to be helping you.(23)

Even when a family thinks that all of the problems have been worked out in advance, as in the case of Pete's subsidized adoption, they soon learn they are confronting a constant series of battles to maintain the supports which they thought were all arranged.

> I was prepared to cope with Pete's physical care needs and his emotional care needs, although they were difficult. However I was not prepared to spend 4-6 hours on a regular basis making phone calls and haggling over supplies and services Pete needs. Especially not with the subsidized adoption program since I had a contract guaranteeing payment of Pete's bills by NYS subsidy until legalization of the adoption and then by medicaid. On 3 separate occasions Pete's subsidy payments to service providers and vendors for equipment and supplies were discontinued illegally. At one point 18 months ago, no payments were made to providers for 4 months. The nurse I employed at the time to take Pete to school was not paid for 5 months. Needless to say, I no longer have a nurse. Due to Pete's unstable condition and to his individualized care and assessment, I am not comfortable leaving him with a nurse who does not know his care intimately. The nurse I lost cared for Pete in the ICU since he was 6 months old. At the time, I felt confident when Pete was in her care at school, so I could spend the time hassling with my supply vendor and the AD program at home on the phone. Now it is much more difficult.(38)

This lack of consistency and the apparently arbitrary actions of multiple public and private professionals intensifies the families feeling of living on the fringe. But now, the fringe is not the one they initially confronted, related to the often delicate condition of their child. Rather they now must deal with the ever present fear that someone will do something to topple their carefully constructed support system, which they all realize is little more than a house of cards. This tension effectively subverts one of the basic principle of family supports: To enable a family to be a family and the parents to devote their principle energies to parenting.

> The family would like to have time as a family but also have quiet time alone just as man and wife, take the kids to grandma's and sleep late once in a while. To get away on week-ends and leave the children home. Mom is pregnant and would like some time to herself. But she won't do it. She is sure that if she leaves it up to the "system" something dreadful will happen. She says she also doesn't understand the role of all the state players who

> come to her home, but every time they make a visit, some of her services are in danger of being cut. (31)

Unfortunately, the conversion of the system and of individual professionals seems to be occurring only on an individual basis. All of the families tell of the consistent professional attitude that assumes incompetence on the part of the parents and family. In many cases this attitude has not changed and when it has this has often been achieved only because the parents awareness showed the professionals some area in which they had made a mistake. The experience of Billy's mother captures this quite well.

> Mom has been fighting the system from day one. She has been Billy's mother, advocate, and primary care-giver and has assumed total care. Dad is not able to respond to Billy's needs, either physically or emotionally. He is combating an ongoing problem with alcohol and Mom had decided to let him get his life in order and she has moved back to her parent's house. There is a large extended family so she feels an acute lack of privacy but has no choice at the moment. The hospital has fought her taking Billy home because they thought that she couldn't do it. He has thrived at home and changed the attitudes of the entire G.I. team about home care and how they treat parents. They have all told Mom they now have new respect for parents and their capacity to take care of their kids. Mom is easygoing and relaxed, and they took this for a non-caring attitude. And only after a long while did their attitude evolve into respect. The turnabout came when the staff made a serious judgement mistake. Mom knew Billy was getting septic and the staff told her she was overreacting and to let them "make those calls" and that she should just stick to being a Mom. They almost lost Billy to infection as a result, and after that things changed dramatically for the better.(05)

John's mother confirms the experience of many families: One of the basic forces driving this "non-system" of home care is the principle of the squeaky wheel. In other words, if a parent is vocal, well informed, and politically well connected then eventually they will get some response from the programs which are supposedly there to assist them.

> Mom has been asking for help since John's birth. She is tired. She finds out about programs and goes for them. She is really her own best advocate.

> She will be inexhaustible where John is concerned. "You are a parent that should have no problems because you know so much and are so strong." That is what a social worker told her. Mom says, "I would rather see a little action than hear that nonsense."(22)

The other side of the squeaky wheel principle is that some families will not get what should be available to them because they do not have the knowledge, strength, or connection to endure. Further, the fact that these services are driven by an essentially adversarial process means even the "empowered" family cannot take the pressure off. This of course puts them under tremendous psychological pressure which is itself a very effective strategy for controlling the demand for services.

> John's Mom even told the Department of Social Services in her county when they did the application for the medicaid waiver that if they had documented the need for all of these necessary services via her MD's "wasn't the county committing child abuse by not putting those services in place?" They did not respond. The Waiver application is still pending.
>
> During this interminable wait for supports, she had her husband call the county to say she was "cracking up and needed help." Their response was, "We can put him on the waiting list, which extends over two years for out-of-home placement." She is furious and says, "I can't even go crazy because they just simply do not care."
>
> Mom also said the same people who did the waiver forms have known John since birth (they live in a small rural upstate county) and are asking for all the medical care history since birth now. "The question I have is what have they been doing in my home all these years!"(22)

Summary and Conclusions

This document represents an effort to examine the experience of families of children with highly specialized needs who, as the pioneers in home care, are defining the future of services. Of necessity, it also looks at the services which are supposed to support the families in their efforts. On one hand we have exposed the reader to the tension between a very traditional approach to services for children with complex medical needs and parents on the forefront of a ground breaking effort. On the other hand the information here testifies to the development of a new definition of the parent-professional relationship as individual professionals and the SKIP case management project strive to work out what it means to support families.

When the testimony of these families is carefully read we are left with an impression of a schizophrenic system of public and private supports for home care for children with severe disabilities and specialized health care needs. The rhetoric of those at the heads of these systems continually affirms the primacy of the family and yet the experience of these families is otherwise. Again and again the families tell of benefits managers, case mangers, discharge planners, social workers, and the like whose actions indicate that they regard the families as welfare junkies out to milk the system for everything its worth. An attitude is conveyed, even in dealing with entitlements and plans to which the parents have long contributed, that the families are the beneficiaries of some benevolent charity and so should be happy with what they are given. Families, who are struggling with coming to terms with their child's impairment and the care demands associated with it, find themselves stigmatized, impoverished, and degraded. In a society of rugged individualists they are forced to ask for help. That in itself is more than some of the parents can deal with. And yet, the system in its machinations throws this request back in their face.

It should be clear that these parents are not asking for charity. No one here is out to "milk the system." In its simplest form these families affirm human community. They are simply seeking support from our communities in meeting some of the extraordinary demands associated with raising their children. As parents, they are not looking for the state to assume their responsibilities. Rather, they seek supports which will enable them to devote their energies to being parents and not exhaust ourselves battling for a few services. They are calling on the state to recognize support for the family as an entitlement which affirms that the family is indeed the cornerstone of our society.

They base this call on the fact that support for families is the most cost effective service the state can provide. By supporting families and aiding the integration of children with disabilities and special health care needs in their home communities and neighborhood schools the state will shape the future demand for adult services in a manner which places much greater reliance on the already existing resources of our communities and less requirement for expensive specialized service settings.

In conclusion, we would like to highlight some of the principle points made in each of the preceding sections of this report. Since the rhetoric of public officials at the highest state and national levels continually emphasizes the centrality of home, community, and family in services to people with disabilities, it is important to look to these summary statements regarding the experience of families for direction in bringing the day-to-day practice of public and private agencies, case managers, hospital, schools, and insurers in line with these commendable priorities.

The Families and Their Children

- The study group is made up of families from throughout New York State who represent the full spectrum of economic and social condition found in the state.
- The children in the study group are distributed across the age range from birth to 18 years. They have a wide variety of disabling conditions.
- The vast majority of children in the study group have multiple diagnoses, very complex medical histories, and a large number have very low incidence disorders.
- The primary characteristic which differentiates these children from other children with a similar degree of physical, sensory, behavioral, or developmental disability is the fact that they all also have specialized health care needs.

Daily Routine

- Most of the children in the study group need almost complete assistance in every area of daily living.
- The majority of this assistance is provided by members of their immediate family.
- The extent of these care needs is substantially more than the families had initially expected

Specialized Care

- Over and above the supervision and assistance which the children in the study group require they also have a regular need for a variety of medications, medical monitoring, and specialized therapy or treatment procedures.
- The majority of the households in the study group require an array of medical equipment of the kind usually seen in a hospital or skilled nursing facility.

- As a matter of course many of these children regularly require careful observation and frequent interventions in order to assure their continued good health and survival.

- In the month before the interviews took place over 30% of the families in the study group experienced an event which seriously threatened the well being of their child.

- Many of the families with the children who have the most complex condition (i.e. those that need the most careful monitoring) report that the irregularities in the system of home health care, especially personnel problems, have compromised their child's health and safety.

- It appears that many suppliers of durable medical equipment, oxygen, and other supplies, which the families need, take advantage of the lack of specialized knowledge to exploit them.

- Many of the hospitals fail, in their process of discharge planning, to properly educate parents about issues related to equipment and medical supplies.

- A large number of the families using specialized equipment report difficulties getting prescriptions for, delivery of, and reimbursement for equipment which would simplify the process of providing care in home and community-based settings.

Impact on the Family

- The families are universal in discussing the ways in which the child's specialized care needs have had an effect on their life style.

- While the care demands, opportunity costs, and financial expenses associated with care at home are substantial, the families are very clear on the positive outcomes associated with their decisions to provide care in the home.

- Chief among the positive experiences of the families are the improvement in the child's condition since he or she has come home and their growing perception of the child with a disability as a full contributing member of the family rather than as just a "sick kid" or an "extension of the equipment."

- Almost every family tells a similar story about the very difficult news concerning the nature of the child's condition being transmitted in an insensitive detached manner that often served to intensify the family's initial problems in coming to terms with the illness or disability.

- In almost every case one member of the household has foregone employment, job advancement, or education in order to provide for the day-to-day care needs of the child with a disability

- Even with all they are doing to provide for their child at home, many of the families tell of professionals who continue to treat them in a condescending manner and seem to be constantly evaluating their fitness as parents and caregivers.

Informal Supports

- The informal support network of these families is rather shallow. In many cases they are almost completely cut off from their neighbors because of the intensive care needs of their child.
- There is little or no evidence of the "generic" resources of the community extending their services to these families. In the few cases where the families have approached the typical resources of the community (e.g., the schools, recreation opportunities, etc.) they have been found them to be very unreceptive.
- Fear and lack of knowledge concerning disability have often contributed to members of the extended family distancing themselves from involvement with the child with a disability.
- The current system of services to the child and family have done little or nothing to build a bridge between these families and their communities.

Financing Home Care

- Most of the families find themselves pushed to the limits economically in order to provide for the needs of their child with specialized health care needs.
- A large number of families report the need to keep themselves impoverished in order to maintain Medicaid eligibility. Without it they would be unable to obtain any coverage for the expenses associated with their child's care.
- Because of the high costs associated with the care of many of these children, many families find themselves subjected to what they see as highly discriminatory treatment on the part of insurers who are seeking to control costs.
- Many families report being given inadequate or mis-leading information about expenses which are covered by their medical insurance.
- Almost every family reported that the paper work associated with their child's care require several hours of work every week and in some cases this was a daily task.
- Families report an incredible duplication of effort related to paper work needed for public and private insurance and reporting requirements demanded by various services.

- With the exception of assistance from SKIP, the families report no help from insurers, providers, discharge planners, or case managers in how to maximize their insurance coverage. As a result some families find themselves approaching the limits on their policy.

- Many services which the families see as crucial to maintaining their child at home (e.g., respite) are not covered by the insurance because most policies restrict coverage to services which are directly related to the child's clinical condition.

- Almost all of the families report substantial expenses that are directly related to the child's care for which they have either been denied reimbursement, have not sought reimbursement (because they realize the expense is probably not covered), or which they have paid out of pocket rather than dealing with the battles entailed in making a claim. These expenses range from the cost of accessible vehicles, increased utility costs, ramps, diapers, adaptive equipment, respite, over the counter medication, and so forth.

Services to the Child

- The two major institutions providing services to the child are the community health care system and the education system. Neither of these systems has made the transition to supporting family-centered community-based care for children with severe disabilities. Families are universal in describing how their request for home care and services in the local school are treated as a unique, unheard of idea, rather than an opportunity to develop policies and practices that were attune to the future direction of services.

- Many of the children receive an extensive array of services from the health and the education system however most of these services continue to reflect the traditional clinic model of treating "the patient," in relative isolation rather than the developing ecological model of supporting and treating the child within the context of the home and community.

- Although the children and their families receive services from multiple agencies and providers, these providers put very little effort into service coordination.

- While the major experience with the system of services has often been negative the positive experience of these families with individual providers underscores the potential for achieving the ideal of family centered care when both parents and professionals are open to a cooperative relationship.

Family Supports

- With the exception of the support they received from the SKIP project, very few of the families received any services which fit the developing model of family support services which sees the child with a disability within the context of the family, supports the entire family, fosters connection with the family's community, and nurtures parent control of the services that effect the life of the family.

- Some of the most progressive family support programs around the country have attempted to develop a system which is flexible and responsive to the unique needs of each family. They have adopted a guiding philosophy which calls on families to tell them what it is they need to maintain their child in the home and them working **with** the families to meet those needs. None of the families in the study group recount an experience which even comes close to approaching this ideal.
- Most families experience services and providers as taking control of their lives rather than assisting them to gain control of their own situation.
- The parents feel a need for services which provide information and referral, contact with parents who have had similar experiences, advise about their rights in disputes with providers, assistance in planning for the future, quality respite, and service coordination. Almost none of the agencies currently involved in their lives provide or support such services.

Effectiveness of SKIP Case Management

- Families consistently identified SKIP as the one true "support" service that they could depend on.
- As far as specific skills the SKIP project was valued for its knowledge of the relevant laws and regulations, assistance in management of care in the home, information regarding both the system of services and individual providers, and the substantial negotiating skills which SKIP staff brought to the support of families.
- Over and above the specific skills of SKIP staff families valued the attitudes with which the staff approached them. They felt that SKIP always approached them with respect. The staff accepted families as they were and worked with them to prioritize needs.
- Working with SKIP gave families a sense that they were regaining control of their own lives.
- The families are almost universal in crediting SKIP with enabling them to succeed in their efforts to keep their child at home. They see it as providing an invaluable resource.

The Families' View of the Future

- The parents view of the future is badly colored by the experience of the past. . They are not hopeful that the "system" will be there to support their children for the long haul.

- The parents in the study group have a clear vision of the way our society needs to change in its attitudes towards people with significant physical and developmental differences.

Crucial Issues

- The experience of the families in the study group demonstrates that policy and practice in both the public and private sector is guided by an old social welfare attitude which sees the professional as a gatekeeper using complex procedures and paper work barriers to assure that only "the deserving" get services.

- Central to this report is the fact that parents and family members are the most valuable resource for people with specialized health care needs and disabilities. In this vein they are also the most valuable resource to the public and private funders and agencies that provide services to these people and yet these agencies abuse this resource.

- There is a clear need for the professional sector to begin to view all parents as competent responsible people who are seeking the best for their child and as such are partners with professionals. The adversarial relationship which many families have been forced into with providers and insurers is intolerable.

- It is crucial that the entire system of public and private services and the individuals working within this system re-orient their thinking on issues of home care and family support. In this regard, there is a massive need for a careful examination of policy and practices. Further, this issue will not be resolved until formal programs of professional preparation begin to provide their graduates with preparation for working in a community-based system of services.

APPENDIX 1

METHODOLOGICAL CONSIDERATIONS IN EVALUATING FAMILY SUPPORT PROGRAMS

A major intent of this project is to conduct an evaluation of a project funded by Maternal and Child Health to provide family-centered case management services to families of children with complex medical needs. This appendix provides background to the methodology for conducting this evaluation. It is broken into three sections: 1) **Issues in evaluation** which examines some of the special challenges involved in evaluating family support programs, 2) **Review of the state-of-the-art** briefly outlines the findings of the limited body of evaluation literature on family supports, and 3) a description of **the evaluation method.**

Issues in Evaluation

The challenge posed by the proposed project is at the heart of emerging family support policies. Just as the growing national emphasis on family-centered, community-based services for children with disabilities requires a reexamination of the system of services for people with developmental disabilities, this new service environment requires a re-examination of program evaluation mechanisms. The evaluator is immediately confronted with the question of determining the most appropriate methods, measures, and sources of data for gauging the effectiveness of programs which, from their inception, were intended to break new ground. Efforts to evaluate family support programs present two major problems: 1) variation in program objectives, and 2) methodological problems.

Variation in Program Objectives. There is little disagreement that the two goals of family support services are to enhance the family's caregiving capacity and to prevent unnecessary out-of-home placement. Most would also agree that achieving these goals is in the interests of children with disabilities, their families, and society. Operationalizing these goals in terms of specific program objectives, however, is another matter. There is a striking lack of consensus regarding ***what*** these programs should accomplish specifically and ***how*** program objectives should be realized. The resulting variation in program objectives and administrative practices impedes efforts to evaluate existing programs because the use of standardized outcome measures is inhibited and programs cannot be easily compared. This problem is apparent on both the system and individual family level.

On a system level, program objectives related to family support goals vary according to the availability of financial resources, political climate, and service philosophy. For instance, one possible program aspiration is to prevent unnecessary out-of-home placement. This goal in turn dictates eligibility criteria such as "at risk of being placed out-of-home." But how should "risk" be determined? Some would suggest that to avert placement crises the notion of "risk" should be interpreted broadly and that all families with a child with a chronic illness or disability should be considered. Others believe that, due to restricted resources, service eligibility should be limited to families where the home placement is clearly deteriorating. Which of these eligibility options is most likely to reduce out-of-home placement? At present, there is no easy solution and this issue remains a point of contention among families, service planners, and providers.

Likewise, consider the goal of enhancing the family's caregiving capacity. Operationalizing this goal into specific program objectives is a complex and often controversial task, and requires consideration of two fundamental questions: 1) how much of the caregiving burden can the state reasonably expect families to assume? and 2) at what point does the state decide that the amount of support required by a family is unjustifiable (i.e., how much support can a family expect)? Not all service planners agree on the best means for resolving these questions. Consequently, there is substantial variance in the services families can receive around the country.

On the family level, specific program objectives are equally difficult to operationalize. This is in part due to the growing recognition that each family is unique and needs varying types and amounts of services. As a result, "programs have increasingly moved from a pre-set pattern of giving the same services to everyone, to a more individualized approach in which parents have more control over both the length and extent of their program involvement" (Weiss, 1983, p. 10).

The current trend to establish programs that can accommodate unique family situations is encouraging. The resulting variance in the services families receive, however, impedes comparison of program strategies and effects.

Methodological Problems. Evaluation of family support programs is also complicated by methodological difficulties involved in the measurement of program processes and outcomes. Examples of such problems include:

- ***The insensitivity of measures to program effects***: Due to the nature of disabilities, service benefits are not always easily or promptly observed. Consequently, Halpern (1984) suggests that current measures may underestimate program effects. Moreover, Weiss (1983) notes that intervention efforts centering on the entire family require that measures be capable of monitoring changes within family dynamics. Such measures have yet to be perfected.

- ***The absence of longitudinal evaluation***: The lack of immediately observable program effects also suggests that evaluation models should be designed to view change over time. Longitudinal evaluation, however, is burdened by a variety of difficulties, including the attrition of participating families, keeping service packages received by families constant, and determining the proper statistical means for assessing change over time (Cronbach & Furby, 1970).

- ***Sampling related problems***: Halpern (1984) notes a variety of sampling-related problems including small sample sizes, the difficulty in employing random assignment of families to service groupings, and variability in the characteristics of families and persons with disabilities.

- ***Mitigating circumstances***: Evaluation efforts can be adversely affected by a variety of uncontrollable circumstances. For example, Tausig (1983) and Herman (1983) note that several states have initiated policies whereby out-of-home placement into institutional settings is actively discouraged. The obvious impact of such policies on parental placement decisions greatly complicates the process by which family support programs are evaluated.

- ***Inadequate causal models***: Due to many of the problems noted above it is extremely difficult to employ group-based research techniques within a causal model. Consequently, the effectiveness of family support strategies remains largely untested in a quantitative sense.

Review of the State-of-the-Art.

To date, very few evaluations of family centered support services have been undertaken (See Wells, Cox, Berliner, Bradley & Agosta, 1987). In contrast, ample effort has been exerted to study family life and to document the utility of particular training and habilitative techniques that might be employed in the family setting. Review of available literature reveals a wealth of information regarding strategies parents can use to teach or otherwise care for their child with disabilities or that professionals can use to instruct parents about self advocacy, teaching, or other relevant topics. In addition, the effects of various situational factors on the family (e.g., availability of services, rural vs. urban life, family characteristics) are also under study.

Discrete findings such as these, while they provide guidance regarding what tools can be made available to families, tell little about the efficiency and effectiveness of support programs. The following sections provide information regarding the limited process and outcome evaluations that have been conducted.

Present evidence suggests that family support services do enhance the family's caregiving capacity. Families receiving services report:

- Enhanced commitment to continued care at home rather than seeking an out-of-home alternative (Zimmerman, 1984; Rosenau, 1983; Parrot & Herman, 1987).
- Reduced overall stress levels (Moore, Hamerlynck, Barsh, Spieker & Jones, 1982);
- Increased time spent away from the demands of care giving resulting in an improved capacity to keep up with household routines, pursue hobbies and seek employment outside the home (Zimmerman, 1984; Moore, et al., 1982);
- Improved skills for coping with habilitative needs (Moore et al., 1982; Minnesota Developmental Disabilities Council, 1983a);
- An improved overall quality of life (Rosenau, 1983).
- Willingness to be taught several of the specialized competencies needed to provide habilitative care (e.g., Snell & Beckman-Brindley, 1984; Karnes & Teska, 1980);

Though the above findings lend credence to the efficacy of family support programs, Herman (1983) warns that unrestrained optimism may be inappropriate. Her evaluation of family support services in three Michigan counties shows that service effects often diminish with time. In fact, after two years of services, few statistically significant differences could be found between families receiving services and those that did not. Moreover, due to the methodological limitations noted earlier, a causal relationship between support services and outcomes is difficult to demonstrate clearly. Thus, researchers remain challenged to develop and implement evaluation models that document with greater clarity the effects of family support services on the capacity of families to provide care.

Regarding the effects of family support services on the overall system of services little is known. One popular claim is that family support services are cost effective because they diminish the need for funding expensive out-of-home arrangements by making it possible for families either to keep their member with a disability at home or have him/her return home from an out-of-home placement. For example, a Michigan official (Stabenow, 1983) estimates that by serving one person at home instead of at a state residential facility, the state saves about $47,000 annually. Likewise, the Aetna insurance company estimates significant cost savings where care for children with various debilitating conditions is provided at home rather than hospitals (Business Week, 1984). Complementing the findings, Brooten et al. (1986), in their study of an early discharge planning program for low birthweight infants, found numerous benefits for child and family, as well as significant cost savings where care at home was promoted.

Though the accuracy of this type information is not easily disputed, it must be weighed against two other findings. First, the overwhelming majority of families do not place their sons or daughters with disabilities or illness out of the home if at all possible. Thus, unless family services are successfully targeted ***only*** to families likely to seek an out-of-home placement, the cost savings realized by states would not be substantial. In fact, in the short term at least, the costs of funding an extensive family support program may ***add*** to the aggregate costs of services for children with chronic health conditions and/or developmental disabilities. Second, review of existing services reveals that once a child is placed out of the family home, few families bring the person back home once services become available. Thus, the cost savings to states in this regard may also not be substantial.

Give these system level findings, the claim that the acquisition of family support services will save states substantial amounts of money has not yet been documented. For some, until such savings are shown, funding extensive family support services appears politically unattractive. However, decisions regarding funding for these services should not be based simply on demonstrations of their cost savings to the state. Numerous other benefits to such programs have been demonstrated on the family level and must also be taken into consideration.

In sum, the qualitative evidence that has been collected documents the efficacy of family centered, community-based services. Families indicate that they appreciate such services, and are satisfied with their effects, including a reduction in levels of stress (Herman, 1983; Rosenau, 1983; Zimmerman, 1984). Further, families report that they benefit most when they are provided with multiple service options (e.g., respite care, financial assistance and parent education) and least when they are offered fewer services (e.g., respite care only) (Moore et al., 1982). This suggests that no single service component is sufficient for achieving the goals of family support, but that several may be necessary.

The quantitative evidence is less conclusive. Much additional work must be done to gain a greater consensus regarding specific program objectives and to acquire sufficiently sophisticated evaluative measures and models. With these developments the effects of support services on the caregiving capacity of families and their placement decisions can be more definitively determined. Moreover, existing services can be modified so that they more effectively match the service needs of individual families.

Evaluation Method

This evaluation is fundamentally an exploration of the degree to which this service has a "positive" impact on the lives of the families in the project. As the preceding discussion makes clear this simple question is not so easily answered. The fact remains that the concepts of family-centered care is an emerging field which is actually being defined by efforts such as this evaluation. The outcomes of innovative approaches are best determined by exploring how they are experienced by the recipients of such supports. What family centered services means in essence becomes defined for future research based on what it comes to mean for the families involved in it.

Hence, the Maternal and Child Health's and SKIP's interest in conducting a systematic evaluation of the case management project comes at rather an auspicious time. The information gleaned from the proposed evaluation will add significantly to the emerging informational base on the topic and may guide the design of ever more effective service approaches.

At this point in time with the multiple challenges involved in evaluating family support efforts a case study methodology with a strong emphasis on interviewing the recipients of service provides the most effective mode of evaluation (Guba & Lincoln, 1982; Yin, 1984). The case study approach, as traditionally defined as an exploratory stage of some other type of research strategy, is particularly apropos for the examination of a program which is intended to help define innovative approaches to supporting families. As Schramm (1971) points out, the case study approach lends itself to examining how a program developed -- "...it tries to illuminate a decision or set of decisions: why they were taken, how they were implemented, and with what results." What may not be quite so evident is the fact that the case study provides a vehicle which is well suited to examining and evaluating the community-based programs, with their inherent diversity. As Yin (1984) points out, the technical definition of a case study has three major components:

> A case study is an empirical inquiry that:
> - investigates a contemporary phenomenon within a real-life context; when
> - the boundaries between phenomenon and context are not clearly evident; and in which
> - multiple sources of evidence are used.

As an approach to evaluation research, the case study has four specific applications. The most evident of these is to explain the causal links in real-life interventions that are too complex for survey or experimental strategies. A second application is to describe the real-life context in which an intervention has occurred. Third, almost any evaluation can benefit from an illustrative case study of the intervention itself. Finally, the case study can explore those situations in which the intervention has no clear, single set of outcomes. All of these applications point to a case study approach as being particularly well suited for examining the SKIP case management program.

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